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ABSTRACT

This text includes all of the plenary presentations from the 3rd European Conference of Deafblind International's Acquired Deafblindness Network. This international conference was the first to focus specifically on older people with dual sensory impairment. Presentations addressed the awareness of the needs of older people with deafblind or dual sensory impairments, the development of policy, and the development of practice related to older people such as gaining new skills, new approaches to communication, and staff training. Presentations included: (1) "Eurolink Age: An Example of European Lobbying" (Marianne Dwarhuis); (2) "Keynote Speech: People Who Become Deafblind in Old Age" (Malcolm Matthews); (3) "Demographic Study on Elderly Persons with Dual Sensory Impairment" (Else Marie Svingen and Marja-Leena Saarinen); (4) "Contact Persons" (Helle Brogger); (5) "Communication" (Liz Duncan and Martha Bagley); (6) "Vision and Hearing in Old Age" (Frank Jorritsma); (7) "Rehabilitation of the Hearing-Visually Impaired in the Netherlands" (Sita Schipper); (8) "Communication Workshop" (Liz Duncan and Martha Bagley); (9) "Survey of 281 Old Persons and Their Practical Emotional and Existential Needs" (Ann Svensson); (10) "International Awareness Campaign" (Anneke Balder); (11) "Confident Living Program" (Martha Bagley).: (12) "Home Instructors, A Programme in Sweden" (Anita Bengtsson and Margaretha Lagerdahl); (13) "Information Provision and Non Specialist Training" (Ole E. Mortensen); (14) "Staff Development" (Lucette Teurlings); (15) "Constructional Behaviour Analysis and the Kalorama Approach" (Jan Prickarts); (16) "Training of Non-Specialists: A Training Package in the Netherlands" (Lucette Teurlings); (17) "Sense in Derbyshire Outreach Development Project for Older People with Acquired Deafblindness" (Sarah Goodwin); (18) "The UN's Standard Rules on the Equalization of Opportunities for Persons with Disabilities in Relation to Elderly with Acquired Deafblindness with Special Emphasis on the First Rule, 'Awareness-Raising'" (Kirsten Janshol); (19) "Think Dual Sensory: Policy and Practice Initiative Department of Health Social Services Inspectorate" (Jeff Bashton); (20) "Plenary Session on UK Policy" (Peter Kaye); (21) "Obstacles to Older Deafblind People Getting a Proper Social Service" (Graham Willets

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and Brian Peaker); (22) "Life Quality Survey in Finland Intervention Programme for Elderly Dual Sensory Impaired Persons" (Else Marie Svingen and Marja-Leena Saarinen); (23) "Quality of Life Research Data from a Demographic Survey of Deafblindness in the Elderly Norwegian Population" (Else Marie Svingen); (24) "A Programme in Northern Ireland" (Richard Devlin); and (25) "Elderly Deafblindness Closing Session" (Marjanna Suosalmi and Malcolm Matthews). (CR)

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"ELDERLY DEAFBLINDNESS"

Proceedings from:

3rd European Conference of Deafblind International's Acquired Deafblindness Network

Marcelli di Numana. 2 - 7 October 1998

Lega del Filo d'Oro

DbI
Deafblind International

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"ELDERLY DEAFBLINDNESS"

Proceedings from:

3rd European Conference of Deafblind International's Acquired Deafblindness Network

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Lega del Filo d'Oro

DbI
DEAFBLIND INTERNATIONAL
The World Association Promoting Services for Deafblind People

Cover photo: Valentino Renzoni, Osimo, Italy

INTRODUCTION

The population of people in Europe aged over 75 is rapidly growing.

Many elderly people have a sensory loss, and some are deafblind or have a dual sensory impairment.

The conference focus was:

- Awareness of the needs of older deafblind or dual sensory impaired people
- The development of policy
- The development of practice related to older people such as gaining new skills, new approaches to communication and staff training

This was the first international conference to focus specifically on older people with dual sensory impairment and marks the recent growth in recognition of deafblindness related to ageing and the beginning of the development of a new area of professional expertise.

The conference consisted of plenary sessions and workshops. These proceedings follow the order of the conference programme. The text of all plenary presentations is included. For workshops the text and / or overheads are provided if these were used in the workshop. Alternatively a short report of the activity in the workshop is given. Finally notes of an open meeting of the Acquired Deafblind Network are appended with details of how to contact the Acquired Deafblind Network and Deafblind International.

Programme for the seminar

FRIDAY 2ND OCTOBER 1998

Arrivals and registration

19.00: Welcome Cocktail

SATURDAY 3RD OCTOBER 1998

9.00 - 10.00 Official Opening

10.00 - 1 1.00 Plenary Session
Eurolink Age: An example of European lobbying
Marianne Dwarshuis (Belgium)

11.15- 12.30 Plenary Session
Keynote speech
Malcolm Matthews (United Kingdom)

14.00- 15.30 Choice of Workshop Session A
A.I. Life In Ageing
Milan Residential Unit. (Italy)
or
A.2.Demographic surveys
Else Marie Svingen (Norway).
Marja-Leena Saarinen (Finland)
or
A.3.Communicator guides and contact persons.
Else Marie Jensen (Denmark)

16.00- 17.30 Plenary Session
Communication
Liz Duncan (United Kingdom)
and Martha Bagley (USA)

SUNDAY 4TH OCTOBER 1998

9.00 - 10.30 Plenary Session
Vision and hearing in old age
and practical consequences
Frank Jorritsma (The Netherlands)

11.00 - 12.30 Plenary Session
Rehabilitation
Sita Schipper and Jan Prickarts (The Netherlands)

14.00- 15.30 Choice of Workshop Session B
B.1.Sharing information on different programmes
(Joint Presentation of countries)
B.2.Communication: expanding workshop from plenary
Liz Duncan (United Kingdom)
and Martha Bagley (USA)
B.3. Survey of 330 old persons and their practical,
emotional and existential needs
Ann Svensson (Sweden)

16.00 - 17.30 Choice of Workshop Session C
C.1. International awareness campaign
Anneke Balder (The Netherlands)
or
C.2. Groups of deafblind people and rehabilitation
Siti Schipper (The Netherlands)
or
C.3. Home instructors, a programm in Sweden.
Anita Bengsson and Margaretha Lagerdahl (Sweden)

MONDAY 5TH OCTOBER 1998

9.00 - 10.30 Plenary Session
Developing Practice:
-Information provision and non-specialist training.
Ole Mortensen (Danmark)
-Staff development.
Lucette Teurlings (The Netherlands)
-Education of older people with dual loss and their family
Martha Bagley (USA)

11.00- 12.30 Choice of Workshop Session D
D.1.Constructional behaviour analysis and the Kalorama approach
Jan Prickarts (The Netherlands)
or

D.2.Staff training in the Netherlands
Lucette Teurlings
and Anneke Balder (TheNetherlands)

or

D.3. Assessing and meeting the needs of older sensory impaired people
Sarah Goodwin and Tony Kirk (United Kingdom)

TUESDAY 6TH OCTOBER 1998

9.00 - 10.30 Plenary Session
United Nations standard rules with relation to elderly deniblind people
Kirsten Jansbol (Denmark)

11.00 - 12.30. Plenary Session
Making policy
Jeff Bashton and Peter Kay (United Kingdom)

14.00 - 15.30 Choice of Workshop Session E
E.1 Obstacles to older daefblind people getting a proper social service.
Graham Willetts and Brian Peaker (United Kingdom)

or

E-2. Quality of life research
Else Marie Svingen (Norway)
and Marja-Leena Saarinen (Finland)

or

E-3. A programme in Northern Ireland
Richard Devlin (United Kingdom)

or

16.30 - 17.30 Plenary Session
Summing up
Presentation of an international awareness
campaign.

WEDNESDAY 7TH OCTOBER 1998

9.30- 11.30 Meeting of the "Acquired
deafblindness network"

Programme Planning Committee:

Anneke Balder: The Netherlands
Jean François Guérineau: France
Malcolm Mathews: United Kingdom
Ole E Mortensen: Denmark
Ann Svensson: Sweden

Local Organisation:

William Green
Lega del Filo d'Oro

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EUROLINK AGE: AN EXAMPLE OF EUROPEAN LOBBYING

Marianne Dwarhuis (Belgium)

Eurolink Age: what does it do?

Formed in 1981, Eurolink Age is a not-for-profit network of organisations and individuals that promotes good policy and practice on ageing in the interests of older people in the European Union. We have members in all member states and we aim to represent all areas of ageing policy and older people's interests: older people's organisations, social welfare organisations, gerontologists, policy-makers etc. Activities can be summarised under four i's:

- Influencing
- Information
- Innovation
- Intergroup

One of our main activities is influencing policy. We aim to influence EU policies so that they adequately reflect the interests of all older people. In this respect we would like the EU to both develop specific policies, aimed at older people as well as to incorporate the notion of ageing and older people into all other EU policy making. Influencing is obviously related to policy development: to this effect we organise seminars in order to develop concrete policy recommendations. Also, we formulate position papers on relevant EU documents, outlining specific policy views and recommendations.

In order to influence properly you need information. So we collect and provide information on relevant EU developments affecting older people, both for our own means and for others (mainly for members). Information is disseminated mainly by means of our Bulletin.

Our innovative activities consist of running two networks of grass roots projects:

ActiVAge - a network that promotes the positive resource of older people,

and Ageing Well - a network that promotes healthy ageing.

Providing the secretariat for the European Parliament Intergroup on Ageing is another very important activity. The Intergroup was founded in 1984 and is now supported by over 100 Members of Parliament. Its members are from all different parties in the European Parliament.

Aims of the Intergroup:

- provide a forum for discussion and concerted action by MEPs with specific interests in EU issues relevant to older people (e.g. carers for older people, age discrimination at work, older people's health)

- to provide regular opportunities for MEPs to exchange views on EU policy affecting older people with representatives of other institutions, e.g. European Commission, Council of Ministers or with other European NGOs and other relevant bodies
- promote the interests of older citizens of the EU in EU programmes and policies

The IGA meets 4-5 times a year during plenary sessions in Strasbourg and are always attended by European Commission officials of the older people's unit of DG V.
We try and build links with other organisations, not only in the field of older people, but organisations active in the general area of social policy: disability, women's rights, migrants, unemployed, poverty...

What do we want from EU policy?

I have said it already but it does no harm to repeat it:

- specific initiatives for older people
  - First Action Programme - exchange of information
  - Seniors' Pass (pilot study is being carried out and results are evaluated by ACE)
  - European Year of Older People (1993)
  - mainstreaming: older people should be taken into account in all policies

Background

Society is ageing. Europe is the 'oldest' continent in the world. The importance of the ageing of society is becoming more and more recognised. The causes of this demographic phenomenon are well-known. On the one hand life expectancy has risen because of better living conditions, improved medical care and scientific developments. On the other, birth rates have dropped significantly. A few statistics to illustrate the current situation:

- 20 % of the current population is over 60 years of age, 30 % over 50.
  This percentage is increasing: by 2010 25 % will be over 60, with the number of people over 80 rising even stronger.
- The ratio of workers to pensioners is 5 to 1 at this moment. By 2040 this will be 1 to 3. This dependency ratio is very important in view of maintaining of the current levels of social protection such as pensions.

The above figures clearly demonstrate that this ageing process brings along several major challenges, such as the following:

- the labour market

Europe is going to need its older workers. Where there was a general tendency to shorten

people's working lives, there is now a discussion in many countries to take measures to introduce flexible retirement, to enhance the possibilities for part-time work and to create possibilities for and access to education, i.e. measures which enable people to work longer.

- financing social security

A large part of the financing of social security depends on the active part of the population. Since the dependency ratio is changing other means will have to be found. In this context, the notion of solidarity between the generations is often mentioned.

- caring for older people in need of care

The number of older people in need of care - the very old - is increasing. Financing and arranging care for this growing number of people needs to be reviewed. It is this negative image which is often being evoked by the term D - bomb: the demographic bomb.

However, this image does need a little reflection. It is too simplistic, too negative. It is true that people are in general living longer, but it is also true that the vast majority of older people are healthy, independent and active and contribute to society in many ways. Medical and technological developments add to this - so one has to be careful with projections and prejudices.

Today's older people are on the whole better educated than previous generations and they wish to and are playing a more active role in society. The time after retirement is no longer viewed as a passive time of rest, but much more as a time which offers possibilities for self-development and activities. Furthermore, older people do contribute a great deal to society. How about the role of the grandparents, taking care of grandchildren, enabling parents to go to work? Or the vast numbers of older volunteers, active in a wide range of activities? Or, a very important example, older people taking care of their very old relatives (an interesting statistic: 75 % of the so-called informal carers belong to the group of over 55s themselves)?

And, last but not least, the fact that people are growing older and live active, healthy lives, is a major accomplishment, it is something positive!

The situation in which we work:

From the above one thing is becoming clear: the ageing of society has vast implications, that need to be addressed and thought about. And this is the same for all countries of the EU.

Therefore, one could expect trans-national co-operation in this important area. So what does the Union do about this? Are there any specific measures?

The history of EU action in the domain of older people has been piecemeal, to say the least. It needs no repeating that the legal competence of the EU is very limited in the social domain: the principle of subsidiarity is evident in this field. If one looks at the

development of EU social policy it is clear that the Treaty of Rome (1957) has a clear emphasis on economic issues. The main aim after all was the creation of a European Economic Community. Social policy has always been struggling from the marginal status within the overall plan of the EU. Social policy is the poorer cousin and older people within that a relatively new - and minor - consideration. However, we can look at this another way:

- if the EU does exist then it should take account of the large proportion of its citizens which are outside the workplace (50%); and the third of its population which is over 50 years of age

The preamble of the Treaty of Rome states that one of the objectives of the EC is the "improvement of living and working conditions of all its citizens".
And of this one of the principles - then older people are included.
The role of Eurolink Age is both within these limitations to improve the situation of older people and work at another level to change these limitations (e.g. IGC, constantly seeking out new areas of competence, new room for manoeuvre).
A quick overview of older people's policies:
It is only in the last ten years that the EU acknowledges the existence of older people. A short overview:
In 1984 a first allocation for measures involving older people was included in the EU budget. A token amount of 600.000 ECU's; significant however, since it acknowledged older people for the first time. The budget line has continued to grow. It is intended to finance research into issues affecting older people, exchange of good practice, conferences and events.
Furthermore in 1984 a Directive on equal treatment for men and women in social security schemes was adopted, having direct implications for pensions. In 1989 a Recommendation for the introduction of a Seniors' Pass, a travel and concession card for older people throughout the EU, was proposed.
In 1989 the Social Charter with its two articles on older people was adopted:

1. every worker in the European Community must, at the time of retirement, be able to enjoy resources affording him or her a decent standard of living
2. every person who has reached retirement age but who is not entitled to a pension or who does not have other means of subsistence must be entitled to sufficient resources and to medical and social assistance specifically suited to his needs

A Commission Communication on the Elderly in 1990, outlining the first EC action programme on behalf of older people, was proposed and adopted, marking the first official acknowledgement by the Council of Ministers of the relevance of older people to the EU political agenda. This Action Programme was limited in scope, aiming to stimulate and support the exchange of information and ideas, and promoting co-operation between Member States with respect to issues of ageing, but a clear signal nevertheless. It ran from

1991 - 1993, with 1993 as the European Year of Older People and Solidarity between the Generations. This year was a big success, which saw a number of interesting developments, such as a Council Declaration of Principles on Older People issued at the end of the Year, and several European Parliament initiatives and reports. The Council Declaration of Principles was a true sign of the recognition of the importance of ageing issues at EU level.

During the first Action programme on behalf of older people efforts were made to create true mechanisms for exchange and co-operation, at all relevant levels: governments (by means of the Advisory Committee - 2 representatives from national governments for every EU Member State), policy research (Observatory), NGOs (Liaison Group) and practical, grassroots projects.

Post Maastricht and Amsterdam, the role of Eurolink Age is within these limitations to both improve the situation of older people and work at another level to change the effects of these limitations (constantly seeking out new areas of competence, new room for manoeuvre).

Following the success of the European Year, Eurolink Age and other organisations in the field felt confident that there would be a follow-up action programme. Unfortunately, it took the Commission 15 months to propose such a follow-up, since other initiatives in the social field, notably in the area of social exclusion, had been blocked. Things got worse form then on – it is not necessary to go into all those details. Because of the absence of a programme, there is also no legal basis for the existence of a budget line for older people's projects.

This has lead the United Kingdom to lodge an application in the European Court of Justice challenging the Commission's plans to administer the funds allocated to the budget line. Pending the ruling of the Court the Commission had already been requested not to make any further commitments from this Budget line. This has meant in practice that the Commission was not able to fund projects, which in reality sounds the death knell for many hundreds of NGOs all over Europe who work tirelessly for the benefit of older people.

Since older people do not exist in the Treaty, we felt it was vital to change this. During the two years leading up to the Amsterdam Summit, the final stage of the IGC, Eurolink Age worked at many levels to get older people specifically mentioned in the Treaty. But despite all our hard work, the outcome was disappointing. Some governments were not to be convinced of the necessity to ensure that the new Treaty would provide opportunities for EU actions on older people. This issue was dropped at the very final stages of the Conference.

However, there was some progress and we have to make the most of what we have now, and be creative in our approach. The new Article 13 in relation to non-discrimination specifically mentions age. And the new Article 137 provides a legal basis for actions in the area of social exclusion (older people were originally mentioned in the Article but

struck out at the very last moment, much to our dismay). And these articles have been used to provide the basis for EU funding in the future.
And the UK has recently decided to drop the Court case – good news, even though the implications of this are not yet clear.
Why does Eurolink Age do what it does?
Europe does not have a competence in this area. So what can we actually achieve? Should we not give up in the first place? Why bother? At the very last minute of the IGC older people were struck out of the draft text. At the very last minute.

We do it

- because EU is EU for all. So that includes older people. Moreover, everyone ages!
- because older people feel the effects of European legislation, just like any other citizen. They feel the effects and should therefore be involved.
- because it works. We have had many small successes, e.g.
  - 1993 Year of Older People and Solidarity between Generations - we managed to get older people mentioned as a target group.
  - In the Equal Opportunities Programme, for the first time women were mentioned as (informal) carers
  - Every year we have managed to get a raise in the budget in favour of older people (until 1995)
  - Alzheimer campaign: 5 MECU in budget
  - IGC: Discrimination on grounds of age mentioned in Treaty of Amsterdam

Many of these results were obtained through close co-operation with the EP!
How does it work: How do we do it:

- pro-active and reactive: we are always there to gather information and to be informed on what the Commission is doing. Since we try to influence as many policies as possible (mainstreaming) it is virtually impossible to be proactive on everything. So on some areas we react to what the institutions do.

The process:

1. Commission: drafts initiatives
2. Parliament: gives its opinion
3. Council: decides

We try to follow proposals from the beginning: sometimes it is because of us that the Commission is actually coming forward with proposals. That is the way it should be. But

more often we go to the Commission to give our opinion. EP is our main ally.
Council is more difficult to influence but we try at the Brussels level by means of the Permanent Representation there. And of course via our members in the countries.
Very often it is creative work: we go through texts just to find an entry for the word old or ageing or sometimes just all - because that gives us scope for older people.

What next?

Just a few examples of what is going on:
There are 5 budget lines proposed for next year. Partly as a direct result of our work. If this works out, projects across Europe will be able to benefit.
The Commission intends to come forward with a Communication on Older People - and we will be there to ensure that this advocates the principle of mainstreaming.
The EP will organise a Senior's Conference in order to better prepare 1999, the UN Year of Older People.
And we will continue to strengthen the organisation by finding new members and working closely with them at Member State and EU levels.

- there are many EU developments which have implications for older people sometimes direct and sometimes as a secondary result only. It is equally important to monitor these and to ensure that older people benefit form these as well.

The PROMISE project

1. Introduction
PROMISE is a project which aims at encouraging the inclusion of older people and disabled people in the emerging Information Society in Europe. It is one of the actions funded under the European Commission's Information Society Project Office (ISPO). PROMISE began in January 1997 and was completed in September 1998. The scope of the project covers all of the Member States of the EU.
The Information Society offers much promise for older people and disabled people. It also poses various challenges in the form of the potential for new barriers to accessibility for certain groups and new forms of social isolation and marginalisation. Against this background, there is a fundamental need for more awareness of the issues of concern, for more exchange of experiences and examples of good practice, and for increasing inclusion of the concerns of older and disabled people in national Information Society programmes and initiatives.
This introduces the PROMISE project and provides an outline of what the "Information Society" entails as well as what it means for older people and disabled people.
2. The Information Society - What is it?
The term "Information Society" has come to be used to describe the increasing

importance and involvement of computers and telecommunications in our daily lives. New structures are emerging in business and organisational life (e.g. "virtual" corporations) and in many areas of social life (e.g. interest groups on the Internet). New activities are emerging as well, including activities that are inherently novel (e.g. surfing the Internet as a hobby or lifestyle) and new ways of doing things that have previously been done in other ways (e.g. teleworking). New ways of relating, based on "telepresence", are also emerging, and videoconferencing, videotelephony, electronic mail and other media enable remote business meetings and supporting new types of social interaction.

Within these broad areas, the Information Society offers numerous possibilities:

- mass networking and information access over services like the Internet
- smart cards and electronic money
- on-line transactions (telebanking, teleshopping)
- interpersonal communications (such as video- and text telephony and electronic mail)
- teleworking
- distance learning
- electronic publishing of and access to information (such as books and newspapers)
- telemedicine
- interactive TV and on-line games.

All citizens should be in a position to benefit from the Information Society.

A basic pre-requisite for participation is that the necessary telecommunications infrastructures and user equipment (telephones, videophones, PCs and modems) are available to all. These enable the connections that allow people to work, communicate and have access to the information products and services that are becoming available. Other important requirements include the necessary knowledge and skills to use the new technologies and services and, particularly for older people and disabled people, the design of the technologies and services in a way that ensures that they are accessible and user friendly.

3. An Information Society for Everyone

Living and working in an Information Society is becoming an increasingly important aspect of daily life in Europe. In parallel with this, the European population is ageing and people are living longer. For older people and disabled people, making up more than 20% of the population, many of the applications and services of the Information Society provide important opportunities for support in maintaining independence, and increase participation and integration into society.

Learning and working in the Information Society

One priority is to ensure the participation of older people and disabled people in the world

of work as the Information Society emerges.

On the one hand, the labour market in Europe will need older workers as demographic trends lead to a situation where there will not be enough younger entrants to meet demand. In many countries discussions are already taking place on the topic of flexible retirement, and on the need for new solutions to support part-time work for older workers and new ways of enabling life-long learning.

On the other hand, the current participation rates of European disabled people in the labour market are low, and disabled people are far less likely to be in paid employment than non-disabled people. This reduces opportunities for independence and equality, wastes an enormous human resource and means that many more people than necessary depend on social security. Opportunities presented by the Information Society in areas like teleworking and distance learning offer many possibilities for increasing the participation of older people and disabled people, not only in the world of paid employment but also in other activities (i.e. voluntary work) which greatly contribute to society.

Independent living

Another priority must be to exploit the possibilities offered by the Information Society to support independent living for older people and disabled people. One aspect of this is the convenient access to goods and services that can be provided by on-line information services, teleshopping, telebanking, pay-TV and on-line entertainment, and other such developments. Another aspect concerns new possibilities to deliver care and support from a distance, such as alarm and other security services, social services (telecare) and health services (telemedicine).

Accessibility

More than 10% of all EU citizens are disabled (at least 37 million people) and 70% of these are over 60 years of age. Not all of the Information Society products and services of general interest are currently accessible to disabled people with various impairments. It is therefore imperative to ensure that their needs are taken into account and that the services and products of the Information Society are "designed for all" and conform to the principle of equal opportunities.

Accessibility of the Information Society means taking into account the different needs of older people and disabled people. For example, people with visual impairments must have access to services and products that offer alternatives to print or visual displays, such as speech synthesis or Braille displays; people with hearing impairments must have access to alternatives to the audio medium, such as text or sign language; and people with learning disabilities must be catered for by using standardised instructions in plain language or symbols. More generally, the design of equipment and services should take account of the needs of people whose dexterity is impaired or whose speed of interaction is slower.

Eliminating other barriers

Other barriers to participation in the Information Society can include low levels of

awareness, lack of affordability and limited availability of useful services in some countries and regions.

Many older people and disabled people are not yet familiar with the concept of the Information Society and are therefore not fully aware of the opportunities and possibilities that can be offered. It is one of the aims of the PROMISE project to raise awareness, not only among older people and disabled people, but also among policy makers in this field.

Although developments in the Information Society are taking place rapidly and more and more people are gaining access to the equipment and telecommunications services that are needed, costs can still be a major barrier for many older people and disabled people. Many actions can be taken by public policy (through public financial support to help meet costs) and industry (through flexible and creative pricing strategies) to reduce these barriers.

Many useful services for older people and disabled people are not universally available throughout Europe. Market forces alone will not be enough to ensure that all older people and all disabled people will have access to the latest developments, no matter where they live. Public investment will also be necessary to ensure that services of general interest are available to all.

4. The PROMISE project - aims, focus and target groups

The main aim of the project is to compile a resource on examples of good practice in using the Information Society for the benefit of older people and disabled people, and to use this to raise awareness and stimulate the development of appropriate actions in all of the EU Member States.

Case studies of good practice

The case studies of good practice will cover the full range of application areas and services that have relevance for older people and disabled people. They will include interpersonal communication (by voice, text, video, symbols and other media), solutions to accessibility issues (ranging from well-designed telephones to WEB pages suitable for visually impaired people), new services and supports (such as teleshopping and telecare) and new opportunities to participate in work and education (such as teleworking and distance learning).

European Colloquium

The case studies will provide an important input to the PROMISE colloquium on 27 and 28 October, 1997 in which representatives of user organisations and policy-makers from each EU country will participate. The aim will be to exchange information on good practice in this field and to develop ideas for encouraging appropriate actions (i.e. awareness raising etc.) in each of the Member States.

Keeping up-to-date with PROMISE

To keep interested parties informed of the progress of the project, a WEB site will be established and a series of three newsletters will be distributed. The WEB site will be available in August 1997 and the first newsletter will also be available at that time.

5. Contacts

The partners in this project are:

- Work Research Centre, Ireland.
  Contact person: Kevin Cullen, tel. +353 1 668 3988 fax +353 1 668 3142 e-mail: 100140.1053@compuserve.com
- STAKES, Finland.
  Contact person: Aulikki Rautavaara, tel. +358 9 3967 2077 fax +358 9 3967 2054 e-mail: aulikkir.@stakes.fin
- Eurolink Age
  Contact person: Christine Marking, tel. +32 2 512 9946 fax +32 2 512 6673 e-mail: eurolinkage@ace.org.uk
- European Disability Forum
  Contact person: Maria Brättemark, tel. +32 2 282 4606 fax +32 2 282 4609 e-mail: info@edf.arc.be

KEYNOTE SPEECH PEOPLE WHO BECOME DEAFBLIND IN OLD AGE

Malcolm Matthews (UK)

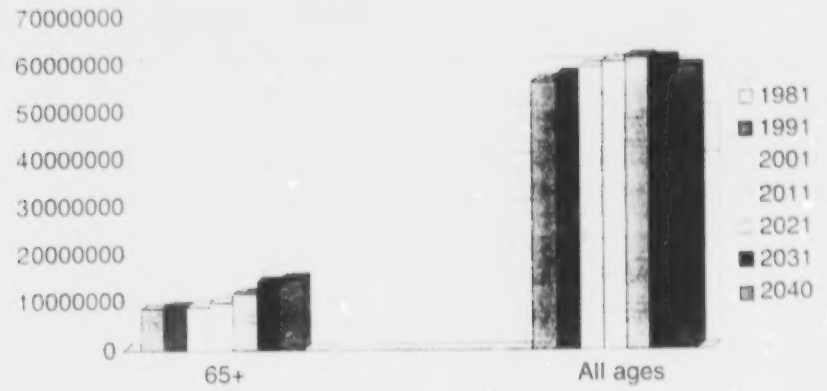
In this presentation I will use two videos. The sound quality is poor so you all have been given a copy of the text. As I show the video you may want to read along with the video or just read the text. Although the sound quality is poor I thought I would still show the videos as these give more of a feel for the situation of older deafblind people.

Through much of the world we are living through major demographic changes, especially an ageing population, with many European countries now dealing with the consequences of an ageing population and many other countries about to face the same problems. As Marianne has said, by the year 2010, 25% of the population of Europe will be over 60 years of age. It is also being said that the number of Europeans aged over 60 is set to double by the year 2025. By that date there may be 113.5 million over-60s in the European Union – making about a third of the total population.

The consequences of change are perhaps sometimes exaggerated by media and policy makers. We see newspaper articles with headlines like "Time running out to avoid elderly crisis" (The Guardian, Monday September 30th 1991). The so called demographic time bomb has been used to validate policy change and reductions in public expenditure (such as in the UK removing the link between pensions and the cost of living). We also see professional groups and service agencies perhaps exaggerating change such as psychiatrists calling for a doubling of geriatric psychiatrists (The Guardian, 24th February 1989) or networks like the Acquired Deafblind Network calling for resources for services to elderly deafblind people. So the question is – is this justified?

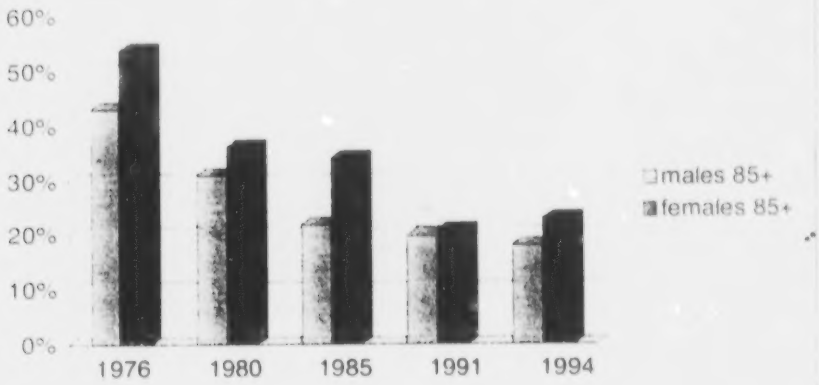
Let's look at the increase in the number of elderly people.

In the UK the number of people aged 65+ increased from 8.5 million in 1981 to over 9 million in 1991, is expected to be over 11 million in 2021 and nearly 15 million in 2040.



Resident population data – UK (Source: Government Actuaries Dept.)

However it is not just the increase in the numbers of elderly people that has been seen as a problem but the increase in the number of elderly people compared to the number of people who are of working age. This is sometimes expressed as the gerontic dependency ratio – the ratio of elderly people to people of working age. In Italy the gerontic dependency rate in 1980 is approximately 21 which means 21 elderly people for every 100 persons aged 16 to 65. Let's compare



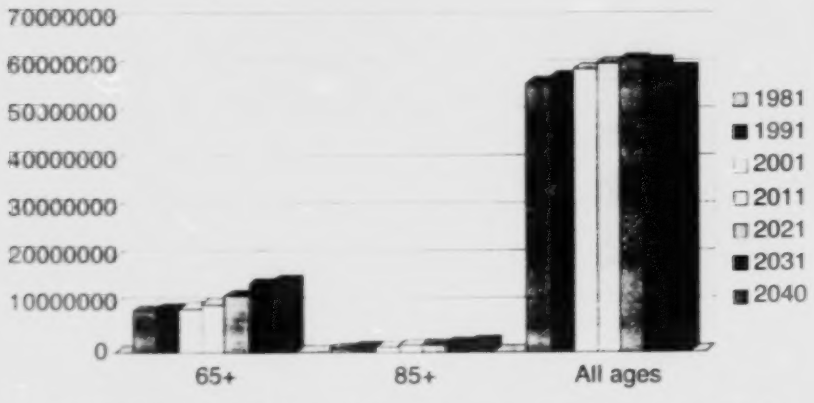
Proportion of people aged 85+ unable to perform activities of daily living independently, 1976-1994

On this chart we can see that the UK gerontic dependency ratio in 1980 is just over 23 rising to 25.5 in 2020. This is a % change of +10%. Italy's rate rises from around 21 to just over 29. This gives a percentage change of +41%. France and Germany have similar changes projected.

It is interesting to see how countries like Japan will soon face the same situation as Europe but with a phenomenal rate of change. In fact the rate of change for Japan should go off the top of this overhead.

Back to Europe though. I'd suggest that these figures tell us that in Europe it is not that we face a major crisis in the future. The extent of growth in dependency is not as significant as the media and some policy-makers suggest – particularly if we take action to enable older people to be active participants in society. Yes we face problems now in meeting the needs of elderly people and there will be more demand – but I would argue that the problems are not overwhelming.

We are concerned about deafblindness and it is the age 85+ population where dual sensory loss becomes common. Let's look at the increase in the 85+ population.

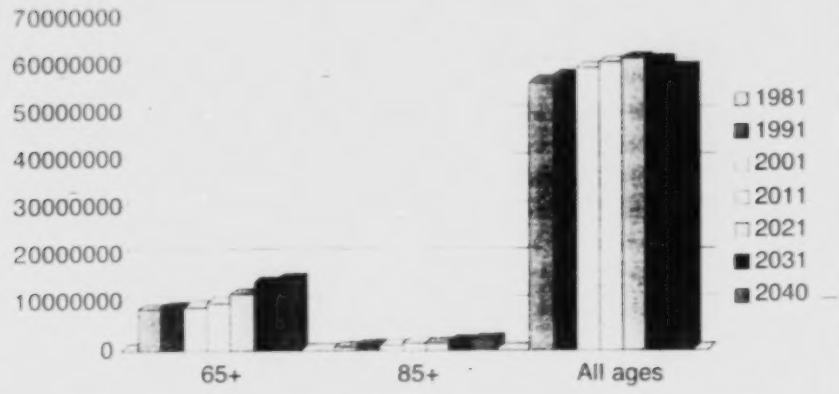


Resident population data – UK (Source: Government Actuaries Dept.)

The number of people age 85+ is increasing particularly as we look further ahead but the actual number of people does not appear so large on a graph particularly when compared to the overall population.

Why are we so worried about ageing? Living longer is something we want provided we are living longer with good health and quality of life. So we need to know whether our ageing population involves people living longer in good health, followed by a short period of ill health and disability, followed by death – or whether increased longevity means a longer period of disability too.

Here there is conflicting evidence. If we look at ADLs, activities of daily living, such as getting up, going to bed, preparing a meal, going to the toilet, then we can see a decrease in extent of disability over time with, for example, the number of people aged over 85 unable to undertake 4 of more ADLs decreasing from around 50% to 22%.



Resident population data – UK (Source: Government Actuaries Dept.)

Our main focus is sensory loss. How does this relate to ageing? Some statistics from the UK. According to the Institute of Hearing Research, in 1997, over 6 million people aged over 60 have some degree of deafness, that is around 70% of people aged over 60 have some degree of deafness. According to the Royal Institute for the Blind 1994 Needs Survey, over 900,000 people aged over 60 are blind. And that is approximately 10% of people aged over 60 who are blind. So what does this tell us about the numbers of deafblind people. How many deafblind people are there?

In the UK estimate a deafblind population of 40 deafblind people per 100,000 of the whole population with 2/3rds of the deafblind population being elderly people. However a survey in Leicestershire identified many more elderly deafblind people.

Ole Mortenson has considered the results of surveys in a few European countries. As a result he suggests that 150 elderly people per 100,000 elderly people are deafblind. This means that, by the year 2025, there may be 168,000 older deafblind people in Europe.

What is the effect of sensory loss for older people? Well we don't often measure it. Looking at ADLs tells us what people can or cannot do but does not tell us why. In the popular imagination failure to look after yourself is attributed to physical frailty. Yet sensory loss and in particular dual sensory loss can affect functioning and ability to

perform activities of daily living across the board. Sensory loss is one of the prime reasons why people can't undertake ADLs. In fact of all the physical conditions mentioned in one study (Bury and Holmes 1991 study of a sample of people over the age of 90 years), "only eyesight and hearing were reported as causing 'total incapacity'"

So if sensory loss and dual sensory loss are so common then why is so little attention paid to them. Why is deafblindness in old age only now beginning to be recognised – as is exemplified by this conference being held.

Perhaps a couple of quotes will be helpful:

Problems that are relatively common in old age such as loss of sight and hearing are often neglected in morbidity statistics (Victor C "Health and Health Care in Later Life" 1991 Open University Press)

"Relatively minor consequences of ageing such as impairment of vision and hearing are virtually inescapable" (Briggs, Open University)

Perhaps sensory loss is seen as a normal or natural part of the ageing process affecting all individuals as they age – and is therefore just something that happens that has to be put up with.

The quote stated "relatively minor consequences of ageing" but dual sensory loss is not a minor consequence.

In a 1991 study [Bury and Holmes] of a sample of people over the age of 90 years "no less than 46% experienced severe or relatively severe eyesight problems. Furthermore, (and as I said earlier) of all the physical conditions mentioned by the group studied, only eyesight and hearing were reported as causing 'total incapacity'".

Do we need to examine what is meant by sensory loss being a natural or normal part of ageing? Do we mean that ageing per se means becoming deaf and blind or is it an increased likelihood of disease over an increased period of time.

Ageing is universal, progressive, intrinsic, and degenerative [Bond et al]. Age related really means related to time. Risk factors are all related to time – biological, medical, lifestyle, environmental – are all time related.

However "The transition from physiological (or age related) to pathological (or disease related) changes can be indistinct. In normal ageing there may be some loss of visual acuity and a greater propensity to cataract formation. Other changes, including most of the 'ageing changes' reported, are in fact pathological (or disease related)" [Bennett & Ebrahim (1992)].

So risk increases over time and some impairment results from normal ageing but others are disease related. Perhaps it doesn't matter whether something is natural or not. The issue is whether or not we do something about it. It may be natural for teeth to decay over time but that doesn't mean that we don't expect the dentist to deal with it – either to prevent decay or cap our teeth or give us false teeth! So perhaps the issue for us is to recognise sensory loss and recognise that we should do something about it.

What is important is our cultural understanding of illness and culturally shaped

expectations of old age. This determines when we seek medical help, the type of help that is looked for, and our judgements of appropriate treatment and care. And we need to recognise that we have different cultures across Europe – not just between states but between, for example, different classes and ethnic groups.

Our attitudes to ageing and to older people need to change. A new attitude is called for as a result of the new demography.

A quote: "First comes an era of socialisation, immaturity and education; second an era of independence, maturity and responsibility, of earning and of saving; third an era of personal fulfilment".

But societal and cultural expectations about how old people should behave and live, about illness and treatment, is not the only factor we need to take account of. There are of course also political factors that determine what happens to people, whether the third era is an era of personal fulfilment.

By political factors I am referring both to policy decisions and ageism – decisions about work and retirement, pensions, long term care and eligibility for services. In many countries access to health services, for example access to medical treatment and aids such as hearing aids, is restricted after reaching a certain age. In the UK you will be lucky to get an assessment and access to aids when you are in your 90s.

Nancy is in her 90s and is now in touch with a Sense project run by Sarah Goodwin. Nancy has both a hearing and visual impairment. She wears hearing aids. With no background noise a person speaking clearly and slowly sitting near to her and speaking towards her ear was usually understood. In this video Sarah asks Nancy about her hearing aids and hearing tests and about eye tests.

Sarah: Who do you see for your hearing aids? Who does your hearing aids?
Nancy: Mmm?
Sarah: Who does your hearing aids?
Nancy: Who?
Sarah: Yes. Well, where do you go? Is it Nottingham that you go to?
Nancy: Yes. Nottingham. Celia takes me. I can't get batteries at Long Eaton at that Sainsbury's.
Sarah: Right, but it's the Audiology ...
Nancy: They go when I want new cable. I go to Nottingham.
Sarah: When was the last time you went?
Nancy: Pardon.
Sarah: When was the last time you went/
Nancy: Oh, I can't remember. I didn't go the last time the hearing aids went because I was bad and it wanted doing. And Celia took it.
Sarah: Right.
Nancy: Oh ... I could tell you.

(Nancy gets up)
I shall knock it over. I don't have those very often. I have a mug. With a flat bottom.

Sarah: Yeah.

(Nancy sits down.)

Nancy: I've got two more in there. I've got four all together. I think it'll be in the newest one.

Sarah: That one?

Nancy: If you can find the ...

Sarah: Shall I have a look?

Nancy: Yes. I can't see anyway.

Sarah: Oh it's very new this one. You weren't there so that one was... October, that one, it would be. Did you go in March, do you remember going in March this year?

Nancy: Yes I probably did. That was before my leg started to be so bad.

Sarah: Right. Did they test your hearing?

Nancy: The October one I didn't go.

Sarah: No. No. But did they test your hearing again? Did they test your hearing or just change the aid?

Nancy: Eh?

Sarah: Did they test your hearing or did they just look ...

Nancy: Oh no. They just did the cables and that ..

Sarah: They just did the cables.

Nancy: They don't do anything now.

Sarah: Do you remember when you last had it tested? Can you remember? Can you remember when you last had it tested? When was the last time?

Nancy: No. The last time I had a test they read to me. They took me in another room where there was glass and that and they got behind this screen and they read something to me. She'd got a trainee with her but he was pretty ... The girl read something and then she passed it on to him to read something – but I could not get a start of what they were reading.

Sarah: No, you see that would make a difference.

Nancy: I had to tell them what they told me but I was telling them wrong.

Sarah: Right.

Nancy: So when we were coming back up the passage to the room again she said, well she says, I'm afraid there's nothing else we can do for you, and that was it. So all they do now they just put a new cable on. Sometimes they put it on right, sometimes they don't. I don't think they just bother ...

Sarah: Would you be happy just to have it tested again? Just briefly, would that be all right, would you mind?

Nancy: Would I?

Sarah: Would you mind just having your hearing tested again?
Nancy: No, because I think it ought to be tested.
Sarah: Right. Was it one year ago that they did that or five years. How long ago when they did that particular test?
Nancy: What this reading?
Sarah: Reading, yes.
Nancy: About. It was about at the end of this other book. Last year sometime.
Sarah: Last year right?
Nancy: I can't remember.
Sarah: No, no. Don't worry.
Nancy: I think I was too disappointed to remember anything.
Sarah: Who looks after your eyes? Who does that? Was that at Nottingham as well?
Nancy: Yes. I go to the Queens for that.
Sarah: And when was the last time you went there?
Nancy: Oh. Em. About three year ago.
Sarah: About three. Yeah. It doesn't have to be exact.
Nancy: But they finished with me.
Sarah: Yes. Yes.
Nancy: Come again my dear when it's gone altogether and we'll see what we can do. I asked the doctor, I said, What can they do? I said yes that's what I think. Nothing.
Sarah: Mmm.
Nancy: It's the blood vessels and the nerves at the back of the eye.
Sarah: Right.
Nancy: You see a lot of people don't think I'm blind.
Sarah: No. No.
Nancy: But my Niece says, You look at people but people who are blind don't seem to look straight at you, she said, but you look at people and she said they don't realise that you are blind. You see my own doctor, my doctor at that time, er, he said if it had been at the front we could have done something but he says with that we can't. So I can't see he can do anything – and when it's gone altogether.
Sarah: Yes. It's .. then it's going to be too late
Nancy: Well that's what I think. But .. they seem very .. He was a new man. The man that I've been having ... This was my first visit to him.
Sarah: Right. Right.
Nancy: I have had an ..... What do you call it, implant. Put something in, stitched it in. A really painful operation.
Sarah: What might be useful is to do an assessment where we work out exactly which bits you are using. If we work out which bits of sight you are using. So, it's just sort of looking round and seeing what you can see.
Nancy: What the ...?

Sarah: For your sight. It's because medically, medically and physically it doesn't really matter. It's how you use what you've got left that is important isn't it?

Nancy: I suppose so. Yes.

Sarah: It's making the best use of ...

Nancy: There's not much left. That one you can say it's gone. It's just black and white. Light and dark.

Sarah: Right.

Nancy: But this one there's just a bit in - and that was the one that went first. That's the one with the implant in – at least I think it is. .... I just hope that bit doesn't go. I can just focus a bit with it. It's gone from the centre to the side.

Sarah: Right.

Nancy: Opposite to Retinitis Regina. That goes tunnel vision – from the side to the centre.

Sarah: So, is it misty? Is it misty in front of your eyes? Or is it patchy?

Nancy: No, it's like a fog. Makes the fog look worse. That's why I think it's so bad, but it's not as bad as I think it is. [Nancy is referring to the weather as it is a very foggy day.]

Sarah: Yeah. Yeah.

Of course the issue remains as to what can we do about deafblindness in old age. We can try and maximise use of remaining vision and hearing, we can improve the possibilities for communication, we can introduce new methods of communication (something that is easier said than done), we can modify the environment, improve lighting, reduce noise, increase contrast, make adaptations, provide aids, teach orientation, introduce use of tactile clues, help with mobility, provide a guide, arrange self help groups, provide transport, organise visitors, support any family, and train staff. But will we?

We are beginning to recognise what can be done but need to work systematically on this. We don't just need to identify and develop interventions that work but need to be able to compare and evaluate them. We need to be able to demonstrate their effectiveness and the value of such interventions even for very old people.

I would argue that prevention and rehabilitation, provision of teaching at the right time when someone is able to learn, provision of aids and support, should be provided at any age. I would argue this on the basis of the effect on quality of life and also the prevention or delay in the need to provide services that maintain the individual in dependency. We can provide someone with the skills to be active participants in their own life by making interventions at the right time or we can fail to intervene and then pick up the pieces later. We can provide ambulances downstream to pull people out of the river or we can spend money on fences upstream to stop them falling in. In the UK we now have eligibility criteria for social services that mean a focus on those in greatest need. This would appear to make sense except when it means that you can get a place in a home when you are in

crisis but not get the intervention when there was a window of opportunity to learn a new skill or receive a service that would have meant going into a home was not necessary or was delayed. In the UK you would be unlikely to receive a new hearing aid or assistive device when you are very old. I would argue for the removal of all age barriers to such interventions. It's a question of our values as a society and how we value human life and human dignity. It's only if we intervene and enable people to access support and services that old age can be an era of personal fulfilment.

A survey of priority areas for health authorities identified services for older people as third in the priorities (after mental health and heart disease), but a little over three percent of extra development money available was allocated to older people. A third of the total resources went to acute services. (By the way disability services was the last in the list of priorities.)

Key issues with regard to services for older people include:

- The balance of acute and community care
- The extent to which expensive ... interventions should be made on elderly people with ... a short life expectancy but where quality of life may be improved significantly for short periods ...
- The extent to which specialist care focused on acute survival detracts from, or undermines, investment in specialist rehabilitation that would raise quality of life for (a reduced number of) survivors.

  [Heginbotham and Ham et al. 1992.]

So we are beginning to recognise what can be done and some of the attitudinal, cultural and political changes required, but we still have the problem of recognition of deafblindness in the first place. If you ask an older deafblind person the question "Are you deafblind?" What answer do you get? Well we will look at that on video in a minute.

Let's look at the effect of deafblindness on quality of life.

The following video is of an interview with Hazel. In the video I ask the questions: "What do you enjoy?" "Do you miss anything?" And "Do you think of yourself as deafblind?"

Malcolm: What do you enjoy ?

Hazel: It's a bit limited now, but I did used to enjoy reading. Not only fiction, I like non fiction books and things like that. I did Moon but as I got older and my fingers got more old it wasn't easy, so I left that. I read large print as long as I could, but I'm afraid that's all out. I just sit and have a doze! I don't feel lonely. People think I am but I'm not, I always find something to do.——— As I told myself when all this was starting about twenty five years or so ago, I told myself to stop being so miserable and to cheer up. I'd got some good years in

front of me yet and they've not been bad. They've not been bad at all.

Malcolm: Do you miss anything?

Hazel: Well I miss those long walks used to have. I don't think you can do them now though. When ——— used to come, he's my friend, he died last year, he was 85 when he died. Before that for about three years he was a very ill man he couldn't walk . I used to go over there and look after him on the weekends.... We went on holidays and that, but he died last year so ever since then when one door shuts, I've always noticed that an other one opens gradually. Well I've had time to get over that you see and I'm just picking things up again. Sarah came to the rescue with Sense, it's given me new interest and knew meaning. So that's one thing..... and another thing you've really got to have a sense of humour. Its no good if you haven't. You've really got to have that sense of humour, and keep it. I've noticed that. When my hearing really went I was withdrawn in to my self and people noticed it. I must have looked a misery, anyway they noticed a change when I got this hearing aid and they started finger talking. But you need that sense of humour, not everybody's got it. Have you got one?

Malcolm: I hope so! I'll tell you a joke later.

Malcolm: Do think of yourself as Deafblind?

Hazel: No! No I don't. When they told me I was classed as severely handicapped, I was surprised. I thought there's worse than me.....I mean where ever you go there's no use feeling sorry for yourself, there's always someone worse of than yourself. I've always thought so any way. I don't. I've not mixed with them much you see, deafblind people. That's what Sarah's trying to do. She wants me to mix more with them and talk to them. Well I appreciate that. When someone comes with me——— they do all the talking and I get left out. So I appreciate that. I've got to do it. So I'm determined to do it. (I don't want to get left out.)

I'd like to pick out a few points:

Hazel is emotional as she speaks about telling herself to cheer up and that the years have "not been bad at all".

The effect of loss – "When my hearing really went I was withdrawn ..." Here we have a key difference between the congenital and acquired deafblind populations. If your deafblindness is acquired then the psychological effects need to be addressed – whether loss is sudden or protracted over many years there will be psychological as well as functional effects.

The effect of ageing – for example on use of touch – Hazel tells us how reading Moon gets more difficult as she gets older.

The value of aids and communication. Hazel talks of the change when she "got this hearing aid and they started finger talking".

The isolation that comes with deafblindness – "they do all the talking and I get left out". The importance of friendship and of being useful, of being able to help others. Going to look after a friend is one of the things Hazel most misses.

In the first video we saw Nancy. I met Nancy sometime after that video was made. She told me about a concert she had been to at the church which she had very much enjoyed. (This I guess demonstrates the importance of not making assumptions about what a deaf person might enjoy.)

Nancy told me about her pet tortoise which she keeps track of by tethering it with a length of string. Unfortunately one day she had tripped over the string and fallen. She had forgotten about this but then her leg had been hurting at the knee and she had gone to the doctor. The doctor had asked her if she had fallen and she had said no. Afterwards she had remembered about her fall and the cause.

Nancy goes to an "invalid friends" group once a month, a weekly visual impairment group, and has just started attending the newly formed deafblind group. She enjoyed the visual impairment group although it was too noisy. The deafblind group was quieter and therefore better.

I asked Nancy about her sight loss and how she felt about it. She told me how when she saw the eye doctor he had said hello and goodbye to her but hadn't said anything else – "He doesn't talk to me" - so she had little information about her blindness. During the conversation Nancy often showed her sense of humour; for example she made a joke about not having to listen to the doctor.

I asked whether there was anything Nancy missed. She said that she wants to go on holiday. Sarah questioned her further on this and established that Nancy would like to go somewhere quiet and flat with no wind. She would be happy in the country or at the seaside. She would prefer a full week not a weekend. I asked about contact with other people. Nancy said that all her old friends are dead but she has a new friend at the visual impairment club. Nancy has three different clubs and some outings and keeps the details of these in her head. She has quite a few people calling to do their jobs; care workers, meal preparation, chiropodist, hairdresser, voluntary agency. These are people doing jobs not social visitors but it was apparent that some of these people took time to take part in social interaction with Nancy.

Nancy said that she had watched the World Cup Final last night on television. When we discussed this it became apparent that she was only aware of a team in blue playing a team in yellow and was aware of the cup being presented. I told her that the teams were France and Brazil and that the score was 3 – 0. I described the cup and Nancy said that it was like a world in a cup. It struck me that it was remarkable to persevere with watching the match with access to so little information. However perhaps the important thing was watching the match as billions of other people were doing – of connecting with human culture.

Nancy talked about her environment e.g. there had been problems with her front door. She said that she had identified that the problem was a hinge through feel.

I have spent sometime on Hazel and Nancy's situation because I wanted to give an impression from their perspective. I could have talked about the isolation of older deafblind people, the potential of older deafblind people, their strength, their humour, their needs. In fact I hope I have done all these things.

To return to my earlier question about recognition of deafblindness. Hazel did not regard herself as deafblind. Most older people who develop their sensory loss in old age will not identify with the label "deafblind". We use the term deafblind usually to try to be clear that we are talking about sensory loss that is not just hearing loss and vision loss but is about recognising the effect of the combination and that different strategies and skills are required that include use of other sensës - for example tactile approaches - and other techniques. We also use the term deafblind to mark out the need for a different discipline that needs resourcing if peoples' needs are to be met. We have a real dilemma here if deafblind people do not see themselves as deafblind but we continue to promote the term. However there is no dilemma over the need for increased awareness. We need recognition that sensory loss and dual sensory loss is part of the ageing process that affects many older people and very many very old people. We need to recognise that sensory loss can radically affect independence and quality of life. But that's not the end of the story. We can do something about it – particularly if we take action at the right time and if we modify our services then the cost need not be great - but the outcomes can be great as measured in terms of maintenance of independence, maintenance of activities of daily living, and quality of life.

Our society's ageist attitudes need to change. Older people can contribute to society and should receive a fairer allocation of resources. We shouldn't see older people as dependent or a drain on society but rather as contributing to society. Longevity is a triumph not a problem. Yes – but we need to enable older people to be independent and contributing and for many that means recognising needs and recognising that we can do something about meeting those needs – and valuing people enough to make the political decisions to provide the resources. In the allocation of resources by the state (in the UK at least) older people are not valued. If we really value older people then we will provide the services that avoid isolation, that reduce dependency, that result in an era of personal fulfilment. This conference is a starting point. But we have a long way to go.

LIFE IN AGEING

Milan residential unit
Daniela Acerbi, Sara Passeri, Teresa Alagia, Virginia Casale (Italy)

The residential unit is a service offered by the Milan branch of the Association "Lega del Filo d'Oro" and it is located in the city centre. It was founded on 26th May 1996 and is the first service of its kind for elderly deafblind people in Italy. It is part of a pilot project whose experimental model could be reproduced in other regions where the Lega del Filo d'Oro already has services or by other Associations willing to make a similar experience. The unit provides support and a social-education service within a community environment. Five people with an average 60 years of age live in the community. They all have a good level of autonomy and self-sufficiency. Each client finds here a structured way of life where he/she can make experiences, participate in the running of the community and actively be part of the decision making. The people living in the unit have made this choice usually because of family situations or accommodation needs.

The staff of the unit is made up of two educators, two technical assistants, a social assistant who comes once a week, three operators for night shifts. Other significant people involved are two conscientions objector, volunteers and a scout group. All staff work on shifts from 8 to 14 and 14 to 20 after this time the night staff take over.
Admission to the unit is made on the client's or his/her family's request or on health authorities' proposal. A fee is due, since the unit provides service assistance. Paid in part by the client and part by local authorities.
The aim of the unit is to respond to the deafblind person's needs by making it possible for him/her to express his/her character and respecting his/her way of life and background. The aim of our work is to guarantee a good quality of life and of assistance, allowing our clients to make significant experiences and be integrated in the social context. We are sure that a person, though elderly, has not yet completed his/her development, therefore we believe in giving value to his/her resources and creating the conditions for each client to choose among information and to make significant relationships.
From our daily work- we noticed that their most important need is to be the main character of their own lives, to be able to make decisions and to receive respect as a person. Our approach is close as possible to the expression "it is not important to add years to life, but life to the years".
In our two-year experience a constant discussion remains open:

- Is a residential unit a service for life?
- Which services guarantee the necessary support until death?
- Is a residential unit a place where an experience similar to a family life is made and

Is this what the clients expect?

- Does the model of a residential unit correspond to the needs of a deafblind person?
- In order to integrate a client in the social context a unit needs the support of the family and how can we restore or maintain the family ties?
- Is it right that an operator asks about the client's family history?

We are sure about one thing: a residential unit is an opportunity for the deafblind person to recover his/her identity and social dignity and to move within a social environment of which he/she is an active member.

This workshop was an attempt to open a discussion on these questions and to share experiences of good practice.

DEMOGRAPHIC STUDY ON ELDERLY PERSONS WITH DUAL SENSORY IMPAIRMENT

Else Marie Svingen (Norway) and Marja-Leena Saarinen (Finland)

In this survey the concept dual sensory impairment is used, although the persons themselves do not consider themselves as disabled. They believe they have problems in hearing and seeing. However, it is easier for an elderly person to identify himself/herself with the dual sensory impaired than with the deafblind.
The study is divided into two separate parts. The first part was a population survey of the number of elderly persons (over 65 years of age) with dual sensory impairment. The second part was a survey of their life situation and functional difficulties of dual sensory impairment related to ageing.

1.1 Background of the research

According to data given by the Finnish Deafblind Association there are 800 deafblind persons in Finland. According to the data 10% of them are children under 18,56% are more than 65 years old and 20% are over 80. 14% of the deafblind are adults and middle-aged.
According to everyday experience there are more elderly deafblind persons than the statistics tell. In order to examine this more specifically, a demographic survey on elderly persons with dual sensory impairment was carried out.
The demographic survey is quantitative and divided in two parts. The survey is developed by the Norwegian Statens Sentralteam for Dovblinde, who at the same time carried out a corresponding survey in Norway. The Norwegian research team offered the opportunity to carry out the Finnish survey with their research method.
In Finland the research was a project by the Service Foundation for the Deaf and it was called a development project on social and health services for the deaf and the deafblind.

1.2 Municipalities involved in the survey

The municipalities in the survey were chosen among Oulu district's welfare cluster municipalities with a lot of elderly persons. The municipalities were chosen among those with actively functioning social services for the aged based on an assumption that personnel in these municipalities would be motivated for research co-operation.
The municipalities were divided according to population into three groups: town-like municipalities (at least 15,000 citizens), densely populated municipalities (4,000 – 15,000 citizens) and country-like municipalities (less than 4,000 citizens). The two town-like

municipalities were the towns of Oulu and Kuusamo. Pudasjärvi, Oulainen and Tyrnävä belonged to the group of densely populated municipalities, whereas Utajärvi was a country-like municipality.

Municipality	Population	Number of persons over 65
Oulu	109,094	11,843
Kuusamo	18,678	2,136
Pudasjärvi	10,958	1,593
Oulainen	8,444	1,314
Tyrnävä	4,083	497
Utajärvi	3,592	593
	154,849	17,976

Figure 1. Municipalities involved in the survey, their population and number of people over 65.

The purpose of the study was to find elderly persons with dual sensory impairment. The survey was focused on clients of social and health services. According to practical experience the average age of persons with dual sensory impairment is around 80 and presumably they already are users of various support services.

1.3 Indicators of the survey

The first part of the population survey consisted of an evaluation form with the help of which the social worker identified a person or persons with dual sensory impairment among her clients. The evaluation form is a functional diagnostic tool. After identification, the elderly person with dual sensory impairment was interviewed. Permission to interview was given by the elderly person herself/himself. The questions were formulated so that they either supported the functional diagnosis of the social worker or proved the diagnosis to be incorrect.

2. Survey procedure

2.1 Population survey of elderly persons with dual sensory impairment within social services for the aged

The municipalities belonged to a welfare cluster the municipalities in which were generally devoted to developing social services for the aged.

The survey team members visited the municipalities. Firstly, discussion and schooling were arranged for people responsible for social services for the aged. Their task was to

carry out the survey and to school the co-workers for the assignment. In each municipality different sectors of social services for the aged were divided into areas of responsibility in order to exclude overlapping.
Social workers for the aged in each municipality participated in a schooling day in accordance with their resources. There was a lot of interest in these schooling days because there was a demonstration of technical aids at the same time and the co-workers had the possibility to discuss problems related to their elderly clients with experts.
The educators were two consultants for the deafblind, a consultant for the visually impaired and an expert on audiology.
During the survey procedure local papers published news about the survey and about elderly persons with dual sensory impairment and their needs.
Both evaluation forms and interview forms were sent to the research secretary. Almost all returned forms included a signed permission for the interview. An anonymous permission was signed by a nurse.

2.2 Population survey on elderly persons with dual sensory impairment in the register of special medicine (1992-1997) – combined register of hearing and visually impaired

Part of the relevant elderly population was found by studying the amount of elderly clients within social services for the aged in the municipalities involved and the other part by studying the registers of persons over 65 in Oulu University Hospital's hearing centre and vision centre. Both centres admit persons referred by a doctor only. A visit to the hearing centre means that the elderly person needs aids for hearing, whereas a visit to the vision centre means that he/she needs aids for seeing.

2.3 Combining the social services for the aged and the register of the elderly

A comparison of the group within the social services for the aged and the group in the hospital register of the elderly with hearing and vision problems was made so that none of the elderly persons appeared twice in the population calculation. The omissions were based on three factors: municipality, age and gender. Finally, after combining the list of elderly persons within the social services for the aged with the registers, there were no elderly persons living in the same municipality at the same age and of same gender.

3. Number of elderly people with dual sensory impairment in survey municipalities

87 relevant elderly persons were found through the social workers for the aged, and after down-loading the registers and excluding overlap an additional 42 elderly persons were found. Thus, the total number of elderly persons according to the survey was 129.

Municipality	Elderly persons in the register	Elderly in social services for the aged	Total amount
Tyrnävä	4	0	4
Utajärvi	7	1	8
Oulainen	7	3	10
Pudasjärvi	7	2	9
Kuusamo	20	3	23
Oulu	42	33	75
	87	42	129

Figure 2. Number of elderly persons with dual sensory impairment in survey municipalities.

In the survey municipalities in Oulu district it was found that 0.7% of elderly persons of the current 17.976 citizens were dual sensory impaired.

- The prevalence of elderly (65+) dual sensory impaired persons of the total population in survey municipalities is 718 / 100.000.
- The prevalence of elderly dual sensory impaired persons (65+) within social services for the aged of the total population in survey municipalities is 484 / 100.000.
- The prevalence of elderly dual sensory impaired persons in the register of special medicine of the total population in survey municipalities is 234 / 100.000.

The survey cannot be methodically generalised to the whole of the country. However, it gives an indication of the number of elderly dual sensory impaired persons in Finland. Information from consultants for the deafblind and from smaller demographic studies made during the last years in Southern Finland, Turku and Tampere support this interpretation. If the results of the survey were interpreted and nationally adapted to the population over 65, there would be 5.000 elderly persons with dual sensory impairment in Finland.

4. Age structure

The age structure of elderly population with dual sensory impairment reaches its peak at around 80 years of age. In this age group there are usually additional functional obstacles related to old age, which add to the functional difficulties of the dual sensory impairment.

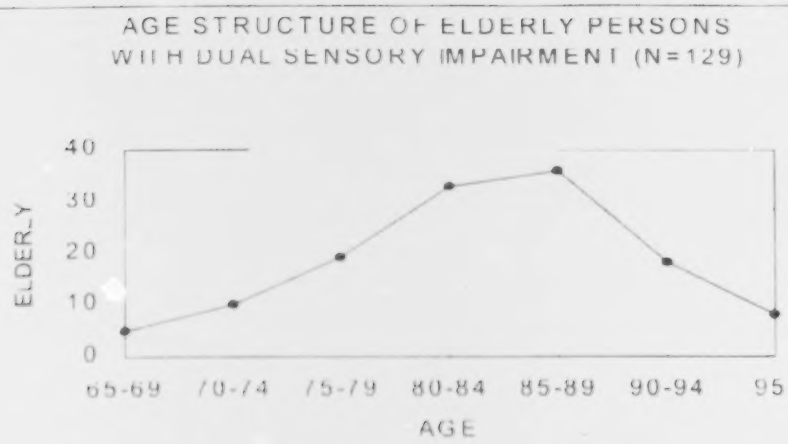


Figure 3. Age structure of elderly persons with dual sensory impairment.

Figure 3 shows that dual sensory impairment is connected with ageing. The average age of all dual sensory impaired persons is 82 years.

The numbers of elderly persons with dual sensory impairmemt are found through social services for the aged. Oulu University Hospital's register of dual sensory impaired persons and population over 65 years in survey municipalities.

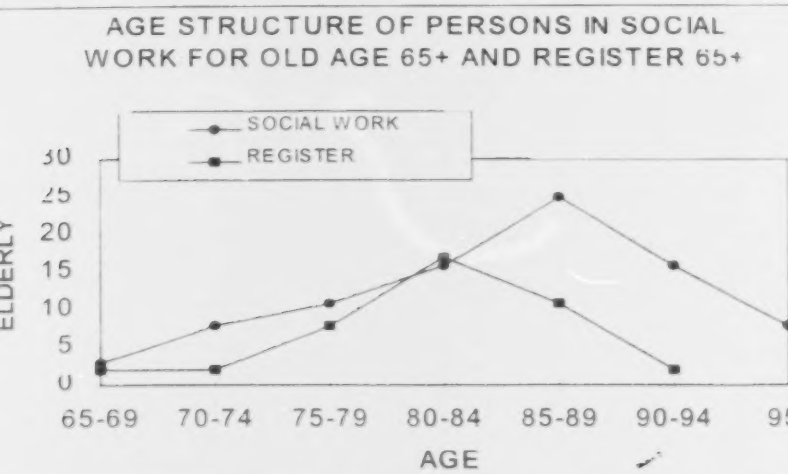


Figure 4. Age structure of elderly persons in social work for aged 65 and hospital register 65.

The structure of age variables of elderly within social services and of elderly in the hospital register is similar. The elderly within social services for the aged are somewhat

older. Some of the elderly persons in the register already use the social services for the aged, whereas others are about to do so.

5. About the number of elderly persons with dual sensory impairment

The number of elderly dual sensory impaired persons can be examined from various points of view. In the following logarithmic presentation special attention should be paid to the relations of the numbers.

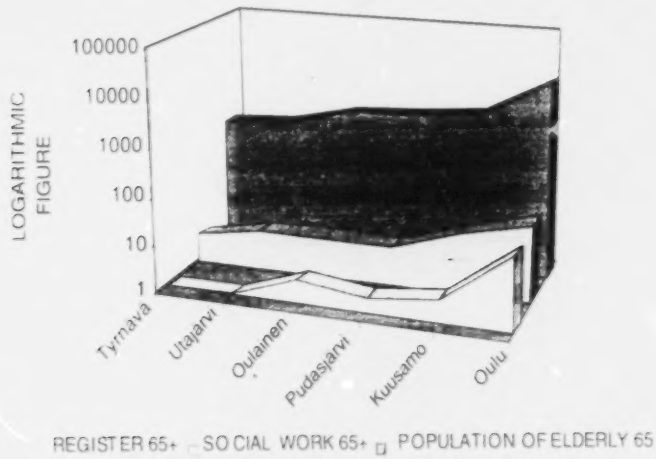


Figure 5. Logarithmic figure: Social services for the aged 65, hospital register 65, total population of the elderly 65

The survey shows that there are elderly dual sensory impaired in each municipality. Figure 6 shows, that only a part of the elderly dual sensory impaired are found among service consumers. Part of the dual sensory impaired elderly are found in registers of special medicine.

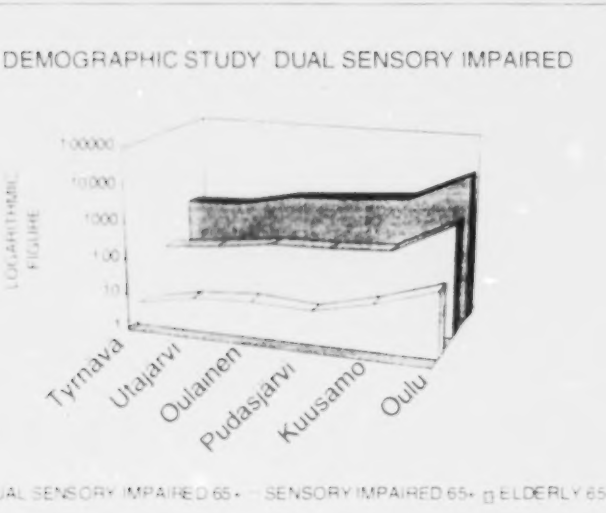


Figure 6. Logarithmic figure: Dual sensory impaired 65, sensory impaired 65, total population of the elderly 65

All elderly dual sensory impaired are not identified within social services for the aged as dual sensory impaired, whereas on the other hand there are elderly dual sensory impaired who do not need these services. It would be interesting to clarify which everyday support procedures the elderly need in order to cope independently or as family members.

Figure 6 tells about sensory impairment and ageing. The total population in the survey municipalities is 154,849 of which the number of elderly is 17,976. In Oulu University Hospital's registers there are 2,055 elderly persons, who are either hearing impaired or visually impaired. According to the survey there are 129 dual sensory impaired elderly persons in the survey municipalities.

It is interesting to compare the number of elderly (65+) sensory impaired with the total number of persons with sensory impairment. Figure 7 clearly shows, that sensory impairment generally – as well as dual sensory impairment – concerns elderly population.

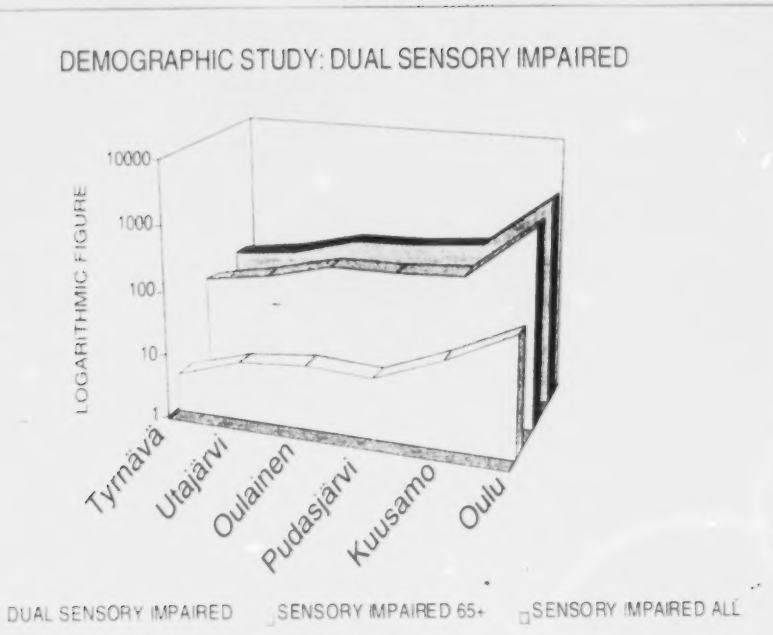


Figure 7. Logarithmic figure: dual sensory impaired 65, sensory impaired 65, all sensory impaired.

5.1 International surveys

In 1994 a survey was made in the Netherlands on elderly dual sensory impaired. This research gives a prevalence of 125 / 100.000.[1]

A survey carried out in Århus district, Denmark, in 1995, gave a prevalence of 130 / 100.000 elderly dual sensory impaired[2]. In this survey 86% of the deafblind in the district were over 67 years of age. The population survey was followed by a survey of the services

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1 Balder, A. & Oliemans P. 1994. Ouderdomsdoofblindheid in Nederland. Stichting Doof-Blinden.
Oliemans Punter & Partners BV. Utrecht. Nederland.

2 Demografisk undersøgelse af antal voksne døvblindblevne i Århus Amt. 1995. Videnscenter for
Døvblindblevne. Herlev. Danmark.

for the elderly and the development of the services[3].
In Norway a population survey was carried out in 1998, the prevalence in which is 129 – 188 / 100,000[4]. The number of prevalence depends on how many elderly persons with hearing and sight problems are considered to belong to the group of deafblind persons.
In a survey carried out in England, Leicestershire, the prevalence was 970 / 100,000[5].

5.2 Comparison with the prevalence in Finland

In the Finnish survey the prevalence was higher than in other Nordic surveys, although Finland used the same screening method as Norway. Differences between Finland and Norway are caused by different implementation methods.
Differences in the numbers are caused by following factors:

1. In addition to the screening of social services for the aged, the register of special medicine was used in Finland. The survey was carried out in the university hospital's district, where the field of sensory impairments is centralised and very well taken care of. There was good access to documented information. All elderly persons who need aids for both hearing impaired and visually impaired were gathered from the register.
2. Another reason worth emphasising is the fact that all survey municipalities were extremely motivated in this identification work. All municipalities participated responsibly. The prevalence in each municipality was comparable.
3. The use of definition in the identification work can be examined as the third reason. In the Finnish demographic survey the Nordic definition of deafblindness was used. The survey therefore recognised all dual sensory impaired persons with functional difficulties in everyday life in terms of both seeing and hearing.

The Finnish survey did not want to exclude anyone on the basis of the "degree" of the person's functional difficulties, but for the following reasons all the identified persons were included in the population:
Age-related dual sensory impairment is progressive.

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3 Ældre dovblindblevnes behov og muligheder for støtte. 1997. Videnscenter for Dovblindblevne.
Herlev.Danmark.

4 Kartleggning av eldre mennesker med alvorlig kombinert syns-og hörselsnedsettelse. 1998. Statens sentralteam for dovblinde. Oslo. Norge.

5 Palmer. B. 1998 Enforced Isolation. Society for the Blind. Leicester. LE5 5FU. England

Dual sensory impairment combined with functional obstacles related to ageing increase the difficulty degree of dual sensory impairment.
In this survey special attention was paid on preventive rehabilitation, which both from the elderly persons point of view and from a national economic aspect is the foundation of the demographic survey.
The purpose of the demographic survey was to find the elderly dual sensory impaired persons and to develop support systems with the help of which the elderly dual sensory impaired can be a part of the life of her/his own.

Results from a Norwegian survey 1996-1997:
"Ascertaining the elderly who have a severe combined visual and auditory impairment".
Introduction:
We intend to give an account of a nation-wide survey of dual visual and hearing impairments in the elderly that was carried out in Norway last year. The Norwegian Ministry of Health and Social Affairs funded the project.
Before presenting some of the results, we first of all, would like to say something about the project's background, targets and methods. We have estimated the prevalence of deafblindness among the elderly in Norway on the basis of these figures. We would also like to say a little about the basis for this estimate.
The background for the survey:
Norway has a nation-wide deafblind register, for which the Norwegian Central Team for the Deafblind is the registration body. Registration is based on functional and medical criteria. Our aim is to offer services and provide information, and registration is meant to assist us in reaching those who need help.
When we started this survey, we knew of around 150 deafblind people over 67 years of age in Norway. Compared with surveys from other countries, we ought to have known of around 800. It was therefore very probable that a number had not been reported to the deafblind register and that the hidden figures were high.
There were several reasons for this:

- In Norway, we lack systems for obligatory reporting on the part of medical diagnostic bodies - public bodies are not obliged to report to the deafblind register. This means that reporting can be incidental, depending among other things on whether people know that the register exists and that special services / rights exist for the deafblind elderly.
- This under-reporting is partly linked to the fact that functional changes which take place in old age are often regarded as a natural part of the ageing process, so that neither the elderly nor those around them associate the combined visual and hearing problems with deafblindness. But we also are aware that changes due to sensory loss can easily be confounded with mental reduction and no adequate remedies made. It was therefore interesting to try out some functional screening

criteria in this survey, to help the personnel who work in the local authority home-help services and institutions for the elderly, to discover deafblindness among the elderly and report to the register.

Objectives:

1. Identify severe visual and auditory impairments / deafblindness among elderly people and in this way help to reveal any hidden figures.
2. Identify need for measures and services like:
   - provide technical aids and training in use,
   - training communicative strategies and give consultancy in how to cope with the new situation,
   - needs for information on adequate services to the individual, his or her family and the health services.

Our target group was:

Elderly people with a serious dual visual and auditory impairment who use home-based services or live in old people's nursing homes (local authority old people's nursing homes or county council psychiatric institutions). According to statistical information, these comprised approximately 25% of all those over the age of 67 in Norway.
We chose this target group based on the following assumption:

- Elderly people with severe loss in vision and hearing are dependent on care from others, therefore they are supposed to live in institutions or receive home-services.

We also assumed that those who are with the target person every day often first discover the practical consequences of sensory problems.
We therefore asked personnel / staff in nursing homes, psychiatric hospitals and home-help services to carry out the charting survey.

Design and method:

The survey was carried out in 2 parts:

1. The charting part - screening
2. "Follow up" phases (Home visits).

Phase 1: The charting part: Screening:

A. Screening for deafblind elderly in all Norwegian municipalities (435)
B. Validity of data:

Check for overlap.

- with register (official)
- incoming data / different sources

Check for false positives ("Follow-up" phase : Home visits)

- clinical examinations
- objective tests

Phase 2: Analysing data:

Identifying needs and define needs and competence development:

- needs in the target group
- needs in staff
- organisational requirements to meet needs

In this presentation we will focus on the charting part of the survey:

The survey material was divided into 2 parts:

1. Materials for the personnel: the screening instrument

- a checklist of the functional characteristics of a severe visual impairment
- a checklist of the functional characteristics of a severe auditory impairment.

(one score on both)

Together with the checklists we sent a description of the selective method:

- The staff was asked to look at the lists of their users and check if they think the persons are matching the lists functional difficulties. If a person gets at least one check concerning hearing problems and one check concerning visual problems, the staff was told to ask the person to join the survey and fill out a questionnaire that covered these subjects.

2. Questionnaire to fill out for the persons picked out by the staff based on screening criteria:

- Background information (Demographics): sex, age, housing, use of local services and technical aids.
- Perceived loss in vision and hearing in general, and in practical situations linked to.
- Communication
- Information
- Mobility

Every municipality got a reporting form on which to fill in the number of people who complied with the screening criteria.

Results: Reported cases from screening criteria:

A total of 1,100 people were reported based on the screening criteria.

336 local authorities answered (77%). 346 of those returned the questionnaire.

There was a great deal of variation between the counties, more than could be expected based on natural variation in a marginal group. Some counties reported a great many people and only four reported fewer than expected. Apart from those targeted, a screening instrument will also pick out a group of people that do not belong to the target group but who are in a grey area. The instrument's level of performance is determined by how well

it picks out the target group and whether it includes many people who do not belong to the target group. To check out if the screening instrument picked out too many outside the target grout, we analysed the answers in the questionnaires and made a comparison.
About a third of those reported (1,100) answered the questionnaire.
From the questionnaires, we found out about visual and auditory problems related to communication, information and orientation / mobility.
Every question had 4 categories for answer. By analysing data we made 2 main categories For answers: "Slight" and "severe" impairments.

Sight impairment	Hearing impairment		Total
	Slight	Severe	
Slight (number)	43	65	108
Slight (percentage)	13%	19%	32%
Severe (number)	62	166	228
Severe (percentage)	18%	49%	68%
Total (number)	105	231	336*
Total (percentage)	31%	69%	100%

The answers to visual and auditory functions based on the categories "slight impairment" and "serious impairment" showed that around 50 percentage of those that answered the questionnaire felt they had severe combined visual and auditory difficulties (hard of hearing / deaf or weak-sighted / blind). These can be assumed to belong to the deafblind group.
Including those who answered "can not hear / see very well", we include those who probably make up a grey area bordering on the deafblind group – some will be included in it and others will not. This grey area makes up around 35 per cent. Around 15 per cent of those who answered the questionnaire stated that they had lost one sense or had a slight combined loss of both senses, and these are felt to fall outside this survey's target group.
Estimated prevalence of deafblindness

We estimate a prevalence of about 130-188 people in 100,000 more than 67 years, depending on how many deafblind there are in the so-called grey-area group.
The basis for this estimate is:

- that the degree of visual and auditory impairment is relatively equally distributed throughout the large group that was reported (1,100 persons) and the group that answered the questionnaire (346 persons).

Some results:
What do we know about the 346 persons that answered the questionnaire?
The majority of the those persons were old, about 85% were more than 80 years. 2/3 of them were women. Quite a high percentage lived in institutions for the elderly or in psychiatric institutions. Of those who were still living in their homes, 70% lived alone.
The majority of those persons had lived their lives as sighted and hearing persons, only few had got a single sensory dysfunction before adulthood or old age.
Validity:
80 people were visited in their homes after the questionnaires had been analysed. Clinical assessments of their sight and hearing and standardised sight tests (sharp-sight and field of vision) were carried out and medical information on their sight and hearing was obtained with the consent of the individual.
When we compared the results after the home visits with the answers from the questionnaires, there was a high correlation between the elderly people's own experience of their sight problems, the personnel's assessments and the objective test results.
However, there was a tendency for the elderly themselves to assess their auditory problems as being less serious than the personnel who visited them felt they were, and for the elderly to feel that their visual problems inhibited their daily activities more than the sharp-sight test would indicate. This confirms that the sharp-sight test is not sufficient to assess the sight function, and that activities that require sight depend on other conditions, such as endurance, concentration, "a steady hand", etc. These can be a problem for many elderly and can therefore make it difficult for them to read.
50% replied to the inquiry of a home visit. 1/3 of these wanted a visit and received one, while 46 persons replied that they did not want us to visit them.
If we look at the visual and auditory assessments stated by the elderly themselves in the questionnaire, the large group of 346 and those who wanted a visit seem to be relatively similar. A total of 113 did not reply to the inquiry, and there may be many reasons for this. We sent a written inquiry, with a copy to the local authority personnel that had helped to fill in the questionnaire. This was to ensure that the replies would not lie unread and so that the personnel might motivate the elderly to accept a visit. A higher percentage of those living in institutions than those living at home wanted a visit. Perhaps this is a sign that the institutions' personnel "sort things out" to a greater extent?

Unfortunately, we did not have the manpower or time to renew contact with those who did not reply. However, information on deafblindness (a video with written material) is being prepared for distribution to all local authorities. Funds have also been applied for so that a research body can follow up this project. We therefore hope that more than just those who requested a visit benefit from contact with the deafblind sector, according to the needs and wishes of the elderly.
The summary from the survey is available in English.

CONTACT PERSONS

Helle Brogger (Denmark)

My name is Helle Brogger. I'm a deafblind consultant in Denmark. In Denmark there are 5 deafblind consultants altogether, out of which 3 of us are working on Sealand and 2 in Jutland.

I'm employed by The Institution for the Deaf in Copenhagen, but my daily work takes place in Jutland. I have an office in Fredericia, which is a town with about 40,000 inhabitants. My work is with people with acquired deafblindness - among whom are the elderly deafblind.

I have got quite a big area to take care of. Some of you might think that Denmark is a very small country - which is true, of course, compared with some of your countries - but having to cover 4 counties, like I'm doing, feels quiet big. I'm spending a lot of time on the road, anyway.

My work consists of giving service to the deafblind. This mean - that I'm going for visits to their homes and trying to expose their need for help.

I find out whether the person belongs to the group of deafblind people - and if so, what can be done in order to help.

One of the things that could be arranged is providing a contact person, which is - according to the Danish law about social services - the right of any deafblind person.

The purpose of this scheme of contact persons is to give the adult deafblind the possibility to get a certain kind of help to break the isolation and to help the deafblind person to live a life as close to normal as possible, in spite of the difficult communication handicap and the need to be accompanied.

The contact person can be granted to people over 18 years of age, and there is no limitation later on.

And then - what does a contact person do?

Point 1: Visiting and communicating with the deafblind:

Just visiting the deafblind person is a very important task, because many of those elderly people really are very ISOLATED.

Most of the old deafblind people I'm in contact with are between 80 and 90 years old. Many of them have lost their partner years ago - often most of their friends, sisters, brothers etc. are also dead.

Their children perhaps live far away or they have a lot of duties themselves taking care of their children and grandchildren and so on.

You also have to consider, that when you are 80 or perhaps 90 years old, you often have other problems with your health - not only sight and hearing - for example you might be walking-impaired or you have other serious health problems. For this reason many old

deafblind persons are not able to take part in a lot of activities - so just to visit them - talk to them - trying to break their isolation is the most important task for the contact person.

Point 2: Giving information about daily life:
This is also a very important thing, because problems receiving information is one of the key issues when you talk about deafblindness.
Most of the elderly deafblind people are not able to read books or to read the newspaper any longer.
Most of them also have great problems looking at the television. Often the pictures are very unclear - and anyway they are unable to read the texts.
Listening to the radio also might be a problem, so having information about what is going on in the world or in the surroundings often is very difficult.

Point 3: Being the link to the surroundings.
The contact person often helps the deafblind person to use the phone, to contact the doctor, the hospital, dentist and so on.

Point 4: Helping with the translation of letters, information, bills etc.
Many of the deafblind people I visit are quite unable to read their own post. I often find that they put aside their letters and bills, until a trusted visitor (for example one of their children) is able to read the post aloud.
It's not rare for the post to have to wait 2 - 3 weeks, until they are told about it.

Point 5: Accompanying in connection with shopping, visits and so on.
Many of the deafblind people are not able to go shopping without being accompanied.
They are unable to cross the road, because they cannot SEE the traffic and often also are unable to hear the noise from cars. In the shops they cannot find the goods on the shelves without help and they are completely unable to read the prices. When they are accompanied by a contact person they again have the possibility to choose for themselves the goods they want to buy.
A short time ago I visited an old lady aged 87 years. She was completely deaf so you had to write to communicate with her. Fortunately she had a little sight left so when you wrote big letters, she was able to read it.
She said to me: "I feel I'm dying slowly, not being able to do anything any longer. I also like going shopping, looking for cheap clothes, when there is a sale, just like you do."
She also wanted to go to museums, to go out-of-doors, and many other things. In spite of her age she still had interest in being informed about what's happening around her, and interest in taking part in activities.
She didn't have a contact person, but I'm now trying to find one for her, and I'm quite sure it will make her life much more satisfying, if I'm able to find the right person.

Point 6: Accompanying - and being the link - to official authorities, post office, banks etc.

These are also important tasks of course, where the deafblind person needs help to be able to have a life like other person in society.

Point 7: Accompanying to activities, courses, meetings and so on.

Often elderly deafblind people have stopped taking part in activities because they are unable to go alone and also because the problems of sight and hearing make communication impossible. If they have a contact person who is giving the information directly to them, they again may be able to take part in activities they perhaps had given up years ago.

THE TASK OF THE DEAFBLIND CONSULTANT IN CONNECTION TO THE CONTACTPERSONS:

Re point 1:

To expose needs and to make the application to the local authorities (the Municipality).

- How many hours a week the elderly deafblind people need is very different and depends on many things:
- How is the sight and the hearing, and to what extend is the deafblind person able to use what is left?
- How many contacts has the deafblind person left? Is there still a partner? How is the contact with the children, the neighbours etc.?
- The need to take part in activities.
- Their health.
- Etc. etc.

Typical the deafblind consultant applies for from 4-10 hours a week, depending on all those circumstances I've mentioned.

Re point 2:

To help the Municipality to find, instruct and employ the contact persons.

To find a contact person is not always very easy, because its so few hours that you cannot live on that alone.

You also help the local authorities with different kind of information, for example, information about wages and how to organise the work.

Re point 3:

To help to find the right contact person for the individual deafblind person (the deafblind must accept the contact person herself)

This is a very important point - that the contact person and the deafblind are well matched, and also that they are able to communicate in harmony.
A short time ago I visited an elderly lady, coming from a high society life. She was 92 years old. As a contact person for her we found a sweet young girl, an intelligent student, but the elderly lady was not satisfied. She didn't know what to talk about when the contact person visited her. She really felt that the difference between them was too big.
She said to me: "She (the contact person) always wears those blue jeans, you know, and a worn T-shirt. I really don't think, she has got anything else to wear!"
The contact person offered to accompany her when she wanted to visit her old friends, but the old lady said: "I just can't bring her to my friends the way she is dressed!"
So now I'm trying to find another contact person - a person with a different style, and an older, more mature person.

Re point 4:
To be a professional support (to the contact persons and to the Municipality).
It means that the contact persons can ask you about different questions in connection to their work, for example about problems with sight and hearing. As I said before, I also have to give information to the authorities if necessary.

Re point 5:
To give supervision to the contact persons.
This we regard as one of the most important tasks in connection to the contact persons.
The contact persons have, as you can imagine, very lonely work, often without any colleagues to discuss problems with.
In my field we offer supervision once a month for about two hours. Usually the supervision goes on in a group but we also have the possibility to offer individual supervision, if there is any need for that.
The contact persons of course always can contact me, if there are any problems.
When we have supervision in groups, we discuss a lot of different problems, dependent on the needs of the contact persons:
We talk a lot about attitudes and about morals and ethics related to work with deafblind people. It is very important that the contact persons respect the elderly deafblind persons rights to decide for themselves.
They must be aware that they are not employed as a nanny or a nurse but they are there to be a substitute for the eyes and the ears.
The contact person has to be aware, that when she accompanies a deafblind to, for example, the doctor, that it is the deafblind person who makes the conversation. The contact person has to be neutral.
Many old people talk a lot about death, which might be difficult for (especially the young) contact persons to handle.

We are taking up these problems, trying to make it easier for the contact persons to handle existential problems in a more professional way.

Re point 6: Arranging courses for the contact persons.

Sometimes we have lessons where we teach the contact persons for example about the techniques of guiding, about sight and hearing, about the social laws and so on.

We also arrange courses where we have other teachers come and talk about different subjects that the contact persons should know about, for example, crisis in connection to loss of sight and hearing.

So as you see, supervision and education is a very important part of our work with contact persons - partly because many of the contact persons don't have any experience with deafblind people in advance, and most of them don't have any education for this work.

COMMUNICATION

Liz Duncan (England) and Martha Bagley (USA)

Issues for older adults who have vision and hearing losses

Martha Bagley

Communication is a process by which meanings are exchanged between individuals through a common system of symbols. This definition implies two or more people are involved in the process and that they are using symbols they both understand.

Communication is important because of the psycho-social implication, social integration, peer acceptance and access to services. People define themselves and understand who they are and how they fit into the world through communication with others. Communication is necessary for integration into the immediate community as well as the larger world. Without it the person become isolated. Acceptance by both family and peers rests largely on the ability to communicate in a way that is felt to be appropriate. Communication is necessary to access services, both rehabilitation services and other basic community services like trash removal, food shopping and such.

Communication Development Guidelines (please see full list developed in Denmark in March 1998[1])

- Communication is the key to other needs
- Development of communication requires time
- Communication is an active process
- Individual choice is critical
- A variety of methods and technical aids may be needed
- Early intervention is critical
- Education and group support are critical
- No one communication system will work for everyone
- Peer acceptance is a major issue

There are two modes of communication with which we must be concerned expressive and receptive. Most older people who have acquired their deafblindness late in life are able to express themselves. They have little problem sending messages to us. They however, have lost their ability to receive communication. It is difficult for us to send message to them.

The Population

- Late life acquired deaf-blind
- Blind late life acquired hearing loss

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1 Proceedings of Expert Meeting held in Copenhagen are available from the Acquired Deafblind Network.

- Visually impaired late life acquired hearing loss
- Deaf late life acquired vision loss
- Hard of hearing/late deafened late life acquired vision loss

Each of these people has a slightly different problem. The issues that must be considered when working with this group are age at on-set, order of acquisition (vision or hearing loss first), and level of impairment.

Liz Duncan

The ability to communicate is something most of us take entirely for granted. The method which we use and how we put the communication together is a fundamental part of our individuality. It display our culture, upbringing, education and perhaps even life history. It is a defining part of who we are.

Becoming Deafblind in later life brings many challenges to the individual, but the greatest challenge comes from maintaining communication and therefore identity. Losing the means to undertake meaningful two way communication is a devastating blow to many older people and is all too often explained away as an unavoidable consequence of the ageing process.

For many, communication can be maintained by adapting existing techniques, for example, large print or by use of assistive devices. Others will need to make the transition to more tactile methods of communication, and a small minority will need specialist expertise and a communication system exclusive to themselves.

However, all older Deafblind people need someone who can spend time with them, establishing "lines of communication". This is a crucial part of the adaptation of communication for older Deafblind people. Beginning communication, exploring methods and topics, and sharing information even on very basic levels, is how we establish a "communicating relationship" and thus begin to understand the communication needs of the individual. This process can be very simple and the relationship established very quickly, or it can be a slow, painstaking process. However as it proceeds, the process requires patience and commitment from both parties. There must be a willingness to communicate from the older Deafblind person and an openness from the communicator, so that all attempts to communicate can be acknowledged and, if possible, explored and developed. Above all, it must be remembered that this is a difficult process for both parties, but that the greater strain falls upon the older Deafblind person. Sometimes it is not possible to establish a communicating relationship, then lack of communication can literally kill.

I met an older man, Elky, in his 70's in June 1997. He was very isolated, unaware of his environment or daily events and there was some suspicion that he was being mistreated by his family. I tried on my visit to make contact with him, but couldn't get beyond acknowledgement of my presence, nor could my regional colleagues. Elky was clearly withdrawn, distressed and very confused but we were unable to get beyond that. His

family were uncooperative and we were denied further access to Elky. In November 1997 I heard that Elky had died as a result of mistreatment by his family - lack of communication was definitely instrumental in his death.

Elky is an extreme example of a complex and long hidden case. There are many people we are able to support who are then able to main effective communication. Some will make use of assistive devices, others will use adapted or tactile techniques and some will use a combination of several methods. For any of these methods to be successful it is essential that the following points are considered:

- Access each individual's existing communication skills and strategies and how these can be continued (possible in a modified form) in the future.
- Assist the person to understand and face up to their condition and likely future changes.
- Take into account the individual's needs, strengths and preferences. These must be sensitively balanced with any aspects that may not be realistic.
- Remember that acquiring deafblindness is a changing situation. Continually assess communication needs, methods and strategies.
- Find out the person's future plans, recreation, interests. The communication methods used must reflect these.
- Consider various technical devices to maximise both hearing and sight.
- Assess for optimum environmental levels in e.g. lighting, furniture, background noise.
- Train those around the person – family, friend, employers – in the chosen communication methods and in the individuals communication needs.

When introducing any new method of communication we must acknowledge the uniqueness of the individual, their current or previous mode of communication, their personal history and current circumstances, as well as the more obvious considerations such as state of health or functional levels of vision and hearing loss. For example, someone aged 94, previously sighted and hearing until over 80 who has several significant health problems, is unlikely to feel comfortable learning to use "hands on sign". However, a combination of large print, fingerspelling and some speech may be more successful, as they are much more closely related to the first language of the individual. It should always be remembered that many older Deafblind people do not perceive themselves as a Deafblind person, and that this message is reinforced by health services and others who see the dual sensory loss as purely a problem of ageing. This can create difficulties when adapting or attempting to introduce new communication techniques.

As mentioned earlier, our method and style of communication is an integral part of our identity and therefore any change challenges not only learning skills but also self perception. This can be exceedingly difficult for people to come to terms with, particularly when they are also dealing with the many other challenges presented by Deafblindness. For the introduction of any new communication technique to be successful, it has to be

introduced at a time when the individual is emotionally ready to accept it, and can adopt it as their own. Hazel spoke to us a few months ago about her experiences of being introduced to Deafblind Manual Alphabet.

Whilst we all recognise the value of introducing new communication techniques as early as possible, particularly if the individual still has some useable sight and/or hearing, Hazel explained that her introduction to Deafblind Manual Alphabet came at a time when she was not ready to accept or use it, preferring instead to continue to use what little sight and hearing she had at that time. Her re-introduction to it came when diminished sight and hearing encouraged her to consider an alternative.

Of course, the challenge of communication for older Deafblind people is much more complex than simply adapting techniques or learning new ones. For a Deafblind person, communication has also to fill in the gaps created by impaired hearing and vision. For some older Deafblind people, the gaps in information may have existed for months or even years. This can lead to an older Deafblind person appearing confused, asking seemingly inappropriate questions, or behaving inappropriately, for example asking if it is Christmas in August, or wearing pyjamas at 2 p.m. in the afternoon (probably very comfortable, but likely to cause a stir in the average home for older people).

It takes time and skill to impart relevant information to isolated older Deafblind people, in a way which is meaningful. It is not enough to merely possess the practical skills necessary to communicate. The communicator must be aware of what information is necessary to the Deafblind person and how to present that information for that particular Deafblind person, therefore making full use of the communicating relationship.

This situation also makes great demands on the older Deafblind person. They must be able to deal with the individual differences between communicators, the different handwriting, speech patterns or tactile pressure. They have to piece together the jigsaw puzzle pieces of communication in order to make the whole picture, but I'll let Hazel explain how she deals with it.

These difficulties are not unique to older Deafblind people, indeed many younger Deafblind people would identify with Hazel's comments. What is unique to older Deafblind people is that they face these difficulties at a time when they are also dealing with the challenges presented by growing older. Often they face all these difficulties without family or professional support and without any of the specialist expertise available to younger Deafblind people.

Older Deafblind people do not require the intensive introduction to the world which is so vital for those who are born Deafblind. They have a wide knowledge of the world around them, based upon many years of experience and interaction. What they do need is appropriate information, advice and support to enable them to maintain two way communication and therefore their quality of life.

VISION AND HEARING IN OLD AGE

Frank Jorritsma (The Netherlands)

Ladies and gentlemen.

I have been asked to share with you what I know of the technical possibilities to help elderly deafblind people. Possibly Anneke Balder asked me to do this because she knows I worked as an audiologist for several years before I specialised in working with visually handicapped people. In the Netherlands multidisciplinary teams do the rehabilitation of hard of hearing people and of people with low vision. The audiologist / low vision specialist is a member of that team, responsible for the assessment of the impairment and the advice on technical aids.

Although I am familiar with the problems both of the hard of hearing and of people with low vision it certainly doesn't mean that I consider myself a specialist in the problems concerning deafblind people. But I do hope that what follows will contribute to the discussion on how best to assist people with this double handicap.

While preparing this presentation I felt the need to clarify for myself what I understand by deafblindness. I use as a definition of deafblindness: the combination of an auditory and a visual impairment.

I do not use the word deafblindness in the sense of the combination of deaf and blind.

I will tell you of my findings concerning the elderly deafblind. To me this seems to be the largest group among both hearing and visual impaired people. I will focus on this group because their impairments are not total and the challenge is to improve their existing hearing and vision with technical aids or technical adjustments.

This challenge concerns a larger group than you may think:

Both in audiology and in visual advice centres the patient population older than seventy is large.

Above this age there is a prevalence of 30% of presbyacusis, hard of hearing of the elderly. So people in this age group who come to a vision advice centre for help have a 30% chance of having a hearing impairment as well.

Above the age of seventy there is a prevalence of 5% of macula degeneration, the main cause of low vision by the elderly. Of course disorders like glaucoma and diabetic retinopathy are also common causes of low vision in this age group. This means that of the people over the age of 70 in an audiology centre you may expect to find 5 to 10% who have a visual impairment as well.

Still my guess from my own experience is that these numbers are underestimated. For instance, when I still worked as an audiologist, I had a caseload of about a thousand patients a year. Among them 4 or 5 were visually handicapped as well. They were blind and came in with a guide dog. Several years later, working both at an audiology centre and a vision advice centre, my awareness of visual handicaps had increased. Almost every

day among my audiology patients I met one with a visual handicap as well. I noticed that 5 to 10% of the hard of hearing patients could be classified as deafblind. These patients came to the audiology centre with their hearing problems. Most of the times they didn't bring up their visual problems. But, during my first year as a low vision specialist we used a questionnaire at the first contact in which we asked our patients if they had trouble hearing. We registered about 30% of the population as having a hearing handicap too. Our criteria were the following: the patient is wearing hearing aids, the patient says he/she should be wearing hearing aids or our impression was that the conversation was rendered more difficult due to hearing problems.

Later on working in a different vision advice centre there was an initiative to improve our help for double handicapped patients. As a start we wanted to count the number of hard of hearing clients we had seen in the previous year. We tried to get an indication by asking all team members to recall which clients they had seen last year with a hearing handicap. We came to an estimate that 4% of the clients were vision and hearing impaired.

By now it will be clear to you as it is to me that a second sensory disability will only be noticed when you are explicitly looking for it.

A beautiful old gentleman came to see me for audiology consultation. His hearing loss was just at a level where hearing aids could be helpful. In such cases I always want to know why someone is coming at that particular moment. Often there has been a recent illness, which wasn't true in this case. I was still wondering till this gentleman warned me not to prescribe very small hearing aids, because his cataract was given him more trouble than before.

Later on in my presentation I will focus again on the combination of a visual and an auditory handicap. But I will start to discuss the two impairments separately. I would like to do this on the basis of the consequences of the disorder. I will not go into the details of the causes of the disorders.

Please feel free to interrupt me if you have a question or if you want a clarification on any of the following subjects. I have my presentation written out on paper here before me, so I should be able to get back into the mainstream...

The ear:

The most common way to describe the seriousness of a hearing defect is the loss in sensitivity to sounds. Normally measurements of barely audible sounds will be made for different frequencies. The results of these measurements are put down in a figure, the tone-threshold audiogram.

The frequency of the tones is put on the horizontal axis of this figure. Normally this scale goes from 250 Hz to 4000 Hz; this means 5 octaves.

To give you an idea about this frequency scale I will give you some examples.

In music 440 Hz is the pitch an orchestra is using to tune up. This pitch is just in the middle of the keyboard of a piano. Melodies are mostly written around this level.

The ground pitch of the human voice is 100 Hz for man and 200 Hz for woman. Vocals are discriminated by their second and third harmonics. The frequencies involved are 200 to 600 Hz.
In music high frequencies help us to distinguish a trumpet from a horn. In speech, these frequencies are important for the discrimination of consonants.
Lets now focus on the vertical axis. The sound intensity is put on this axis. The zero line at the top is the line of normal hearing level. Every point on that line has a standardised sound intensity. This intensity is the threshold for young persons with normal hearing. Downwards the sound intensity increases with a logarithmic scale, the decibel. This variable is a quotient between the measured sound intensity and that of the normal hearing level. Three-decibel means a doubling in sound intensity.
I will give you some examples to get acquainted with this scale. A forest at an almost windless day produces 5 to 10 dB. Whispering is done at 25 dB, normal conversation at 65 dB. We yell at 80 dB. A disco produces 100 dB, a «good one» 110 dB. Sound intensities of 120 to 130 dB are painful.
We always measure the threshold. You may ask are they very meaningful. They are not! They only tell us which sounds can just be heard. Of course the world of sounds doesn't exist of barely audible sounds. We communicate at a sound level of 65 dB. Why then are these threshold measurements still done? Threshold measurements are the easiest. Different kind of hearing impairments are characterised by the measurement result of the tone threshold audiogram. Progression of the hearing impairment can be very well measured this way.
This measurement is so common in audiology that the numbers on the vertical axe are often interpreted as a percentage. The average loss over the different frequencies in decibel is therefore often called the percentage of hearing loss.
The tone threshold gives rather poor information about the impairment that the hard of hearing patient experiences. We must look for other characteristics in hearing to describe the impairment more fully.
The second characteristic can also be put in the audiogram. The bottom line in this figure, the 120 or 130dB line, is the pain threshold for normal hearing persons. In most cases of hearing disorders this pain threshold is shifted to lower sound intensities. Most hard of hearing people have much more trouble with loud sounds than normal hearing people have. So the dynamics for sound intensities is diminished on both sides of the intensity scale. This means that when the intensity of sounds increases the sensation of loudness increases more rapidly for hard of hearing people than for normally hearing people. This has an important implication for amplification of sounds. The loss at speech level must be compensated, not the loss at threshold level. As a rule of thumb a hearing aid amplifies half the threshold loss.
The individual pain threshold is used to limit the maximum sound intensity the hearing aid can produce.

The loss in pitch discrimination is a third characteristic of hearing disorder. A normal ear can distinguish pitch very well. We can hear subtle distinctions. This is of all importance for speech understanding.

There is no simple method to measure pitch discrimination directly. In audiology the disorder is measured by its effect on speech discrimination. At different sound intensities lists of words are presented in the test. The patient has to say what he or she hears. The score of correctly understood words or phonemes is put in a speech audiogram. In this figure the sound intensity is put out on the horizontal axis. This axis corresponds with the vertical axis in the tone threshold audiogram. The score of the speech understanding is put out on the vertical axis. A normal hearing person has a 50% score at an intensity of 25dB, the level as in whispers. At 40dB he obtains a 100% score, a much lower level than the normal speech intensity of 65dB.

In this figure the curve of a hearing impaired person is shifted to the right. The shift corresponds with the hearing loss. The maximum score in the speech audiogram is the maximum benefit a hearing aid can give.

This measurement of speech understanding is done in a silent room. This underestimates the real task for the ears in daily life where there is always background noise. A fourth problem arises.

Background noise is low-pitched. Low-pitched sound has the characteristic to mask higher pitched sound. For hard of hearing people this phenomenon is stronger.

The seriousness of this problem can be measured with speech understanding in background noise. There are standardised methods to do so.

Modern hearing aids try to accommodate these problems.

Shortening the distance between the speaker and the listener is helpful too, by means of hand held microphones, induction loops or radio transmitters and receivers.

My final point of consideration is directional hearing. Our ears receive sounds a bit differently, depending of the direction of the sound source. Through the co-operation of our two ears we are able to hear the direction of sounds. This gives us the possibility to concentrate on that sound.

The possibility of directional hearing will be distorted when there is a difference of hearing ability of the two ears. By the fitting of hearing aids this must be kept in mind; the desirability for two hearing aids must always be considered.

Ladies and gentlemen, thus far I focused on different disorders in hearing. Now, I will give you an overview of technical measures to minimise the hearing impairment.

Amplification of the sound is an obvious method. Hearing aids are just doing that. The oldest form is the acoustic horn; for instance the one Beethoven used. This instrument is actually performing two tasks. A considerable amplification is achieved, up to 15 dB, and the front-end opening is held closer to the speaker, which gives preference to the speech sound above the background noise.

Holding your hand behind your ear has only an amplifying effect.

Lets go back to the electronic hearing aids. They are the commonly used instruments to help hard of hearing people. There are a lot of choices to be made in fitting these instruments. From the tone threshold audiogram, the half gain rule, and the shift in the speech audiogram the amplification of the hearing aid is calculated. The chosen hearing aid must give this amplification when the volume knob is in the middle position.
Then the frequency characteristic is specified. The shape of the tone threshold audiogram is used. The half gain rule gives the amplification for the different frequencies. The amplification in the lower frequencies will be chosen lower than the outcome of the half gain rule. This is done to avoid the masking of the higher frequencies by the lower frequencies. With the result of this calculation a hearing aid can be selected.
The step to limit excessive sound levels is to be made next.
The simplest method is a peak clipper. The amplification is fixed. When the output reached the maximum level the amplitude of the soundwaves are cut off. Although the pain threshold is not exceeded it is at the expense of distortion. The sound quality decreases enormously. You can compare this with listening to a small radio at high volume.
Automatic gain control is a more sophisticated method to avoid the output sound of a hearing aid becoming too loud. Automatic gain control means that the amplification decreases when the sound level becomes too high. By this method there is no distortion. But other negative effects are introduced.
A blind patient explained this very well. He consulted me after a trial period with new gain controlled hearing aids. He disliked these hearing aids because once in awhile sounds became softer. It interfered, he said with distinguishing distances. When you have no visual mark of distances, sound intensity is a good alternative. Your hearing aid should not change this.
New developments in hearing aid design accept the fact that a hearing aid may change its performance in different situations. About 10 years ago the programmable hearing aid was introduced. The wearer of this hearing aid could choose between up to four different programs, different combinations of frequency characteristic and/or maximum level limitation. Next came hearing aids in which different sound levels automatically change the frequency characteristic. The latest digital hearing aids have very complicated control strategies, designed to increase speech understanding.
Consonants are less masked by their preceding vowels. Fast interchanges in the hearing aid achieve this. New fitting strategies are developed for these hearing aids. I don't have experience in fitting them myself, but my audiology colleagues tell me that it isn't an easy job.
These new developments try to achieve better speech understanding in spite of diminished dynamics to sound intensities, the masking of the consonants by the vowels and the masking of speech by noise.
There are other possibilities to conquer this speech in noise problem.

I have already mentioned the possibility of the hand held microphone and the induction loop. I pointed out to you the importance of keeping the function of both ears in balance. With the ability to hear the direction of sounds you can direct your attention to the speaker. Most of the time speakers will be in front of you; you are looking at them. Hearing aid microphones that are more sensitive to sounds in front of you than from the sides are developed.

All these developments aim to improve speech understanding. This certainly is very worthwhile. But it may be that hearing aid designers have underestimated the importance of surrounding sounds.

Our hearing has a second function apart from speech understanding. I would like to call this the warning function. Thanks to our hearing we are constantly aware what is going on around us. We hear sounds from our surroundings. Most of these sounds don't ask for attention; we don't actually hear them. This doesn't mean that they are unimportant. These well known-sounds give a feelings of security.

Once in a while an unexpected sound invites our awareness. We react immediately.

We react completely differently to expected and unexpected sounds. This is only possible when there is an immediate recognition of sounds. This is done constantly on a subconscious level.

Changes in the performance of your hearing aid may influence this particular quality of hearing. Ordinary sounds may not be recognised as such. They are interpreted as uncommon sounds and ask for action. Your feelings of security are affected.

These developments in hearing aids technology have a negative effect on the warning function. An audiologist must be aware of these effects. During the trial period with new hearing aids these negative effects must be outweighed. This can only be done when the trial period is long enough, at least a month, and when the hearing aids are worn continuously during this period.

This requirement is even more necessary when patients suffer from low vision too.

The attempt to keep directional hearing intact serves both speech understanding and the warning function. Sounds are better recognised if their direction information is available. Confusion arises when a sound and the direction from which it is heard don't match. For instance, the sounds of a closing door from the direction of a blind wall, or the dripping of water in the opposite direction of the faucet will ask two interpretations: What does the sound mean? What is happening there? This costs time and a lot of energy.

Attention should also be paid to improve communication conditions. Communication is interactive, so both the speaker and the listener have responsibilities. Avoiding noise should be their priority.

Aspects to take into consideration are. Speak one at a time. Turn down radios and televisions. Avoid large noisy places.

Please don't yell at hearing impaired people. By yelling vocals become louder and increase their masking effect, while consonants stay at the same level. Decreasing the speaking distance is a better solution.

Try to have good illumination on the face of the speaker to improve lip-reading.
Speak slower to give the listener time to understand. Speech understanding is an active process. A listener has expectations about what is coming next. During the process of listening you are checking if your expectations are correct. When in case of hard of hearing you get less information this control function takes more time because you check out more possibilities.
Unexpected changes of subjects are a burden to this control strategy. So changes of subjects must be made explicitly.
Let's consider places where people meet and where being hard of hearing is quite common; I mean houses for the elderly and nursing homes.
In the Netherlands resident lounges in nursing homes are always large rooms, where many people are talking while coffee is being served. People are walking in and out. There are practically no facilities taken to deaden the noise. I wonder why interior decorators of these nursing homes don't pay special attention to acoustic problems and use more sound absorbing materials and make cosy corners.
I would like to finish this item about the ear by telling you something about alarm signals. They can be adapted to the possibilities of one's hearing. Most people with a hearing impairment can hear bells with low pitch better than high sounding ringing.
There are also visual alarm signals, although not always usable for double handicapped people.
Vibration alarms are an alternative:
I met a 40 years old deaf patient. I explained to him the possibilities of the vibration alarm. He remembered his grandmothers' solution. At her front door you had to pull the bell. Inside a piece of wood was placed with one end on the bar of this bell. On that piece of wood a stone was placed. When you pulled the bell, the piece of wood and the stone fell on the floor. You could feel the trembling all over the house
With this old practical wisdom in mind I would like to summarise some of the newer aspects of audiology for you.
The tone threshold alone doesn't describe the disorder sufficiently. Additional information is necessary by knowledge about the sensitivity to high intensities and to the pitch discrimination.
This information is needed for optimal hearing aid selection. New developments in hearing aids improve the possibility of speech understanding, but they may not improve the warning function of hearing and cause feelings of insecurity.
In addition to hearing aids the speaker and the listener have to adjust in behaviour to improve speech intelligibility. Attention should be paid to the acoustics of the rooms in which conversation takes place.
Are there any questions at this point?
For I will leave the subject of the ear for now and go on to talk to you about low vision. I will more or less follow the same strategy in presentation as before.

The eye:

The assessment of vision starts with the measurement of visual acuity. A chart with letters or numbers, every line smaller than the preceding one, is placed 6m in front of you. You have to read these letters as far as you can. A normal seeing person can distinguish a detail as small as 1 minute of arc, letters with a height of about 9mm at the distance 6m. People with normal vision have visual acuity 1 by definition. Visual acuity is defined as viewing distance divide by letter height. Therefore the letter height of 9 mm is defined as D=6. Letters two times as big are called D=12 etc. Then visual acuity is 6/12 or 0.5.

The first developed charts had only one letter at the top level.

Newer charts have 5 letters on every row: the distance between letters is proportional to the letter size and the increment in letter size is constant. Often a shorter viewing distance is used for low vision patients. When this distance is well considered in calculation of the visual acuity this can be done.

This measurement is easy to do: the progression of eye diseases can be followed well. Moreover, the same letter chart is used to measure refraction, the power of glasses, which must be controlled in every low vision assessment.

But, with this measurement we only determine the smallest detectable detail you can see. You can see such small details only when you look directly at objects. Even with good eyes you can't see details from the corners of your eye. So the result of this measurement only tells about the function of your central vision.

Although visual acuity is a measurement of quite another class than the sensitivity loss in hearing, visual acuity is often used for the need of people to express their impairment in a percentage. Here too, the description of the disorder with one parameter is not sufficient.

The sensitivity to light is the second important parameter both for the ophthalmologist and for the low vision specialist.

The ophthalmologist is interested in threshold values all over the visual field. To measure these values lights can be projected in a half sphere. The centre of the sphere has to be fixated. On many spots of the sphere the lowest visible intensity level of the light is determined. This is done after adaptation to the dark. The results of these measurements give the ophthalmologist diagnostic information.

For the low vision specialist these measurements are valuable too. In daily life we are not adapted to the dark and not interested in the lowest light intensity. Still this measurement could give an indication that problems in the visual field may arise.

When low vision patients have problems with their mobility, information on their peripheral visual field is needed. An extreme example of peripheral visual field loss you know by the name of tunnel vision. People with this disorder may have relatively high visual acuity but miss a lot of visual information.

The next point of interest is the effect of illumination on performing different tasks. There is a relation between the smallest visible detail and the illumination level in normal vision. At threshold an increment of the illumination level can be more effective than magnifying

the object. This is why microscopes have light focused at the object table.
In the normal process of getting older, people at the age of seventy have a need of a 20 times higher illumination level than at the age of twenty.
Many low vision patients experience better visual functions at the higher illumination levels. But there are exceptions.
We measure visual acuity with illumination levels of 100, 200, 500 and 1500 lux; 500 lux is the standard level. We change the illumination level in the room between 200 and 1500 lux and ask the patient which level he or she prefers. We also change the illumination during the reading task. We measure the chosen level. From this measurements we get an impression if illumination level is an important parameter for this patient. We know if a low, a normal or a high level is needed.
We remember from audiology that most hard of hearing people are oversensitive to high volumes. What do we find in case of low vision?
Complaints at the relatively low levels indoors are mostly due to infections in the cornea. Light falling on these infections is painful.
More often there are complaints about high illumination through sunlight. A distinction must be made between an over-sensitivity to light and the nuisance of light shining directly in the eye. Especially the elderly often have trouble with this direct shining light. The transparent parts of their eyes are not as clear as before. Entering light is scattered and gives mist all over. Visual functions are diminished dramatically. This effect is called glare. You experience this in your car when your windscreen is dirty and the sun is standing low. You don't have any trouble when the sun is behind you, but you can't see anything when you change direction and you have the sun in front of you.
To quantify glare visual acuity with a standard light level shining in the eye is compared with visual acuity without that light. The results of this test must be considered with care. The effects of slow adaptation to changing illumination levels, the changes in pupil diameter and the sensitivity to high illumination levels may interfere with the results.
I just mentioned the next disorder a low vision patient can experience: a slower adaptation to changing illumination levels. A complete adaptation from light to dark takes 10 minutes, even for a normal eye. But the adaptation to the changing levels we encounter walking around in between sunlight and shade will take considerable less time. In several eye pathologies this adaptation process is decelerated. Visual performance becomes less in the first few minutes after entering another light condition. Entering or leaving the shade, a building, a room can be very awkward for a visual impaired person.
Adaptation speed can be measured, but this test takes considerable time. Often the complaints of patients give us enough guideline which measures must be taken.
Normally visual acuity is measured with black letters on a white background. These letters have high contrast to their surroundings. Contrast can be defined as the difference between the two intensities divided by their sum. Grey letters on a white background have lower contrast. A normal eye can see contrasts as low as 0.5 to 1%.

In low vision the possibility to detect objects with low contrast is often diminished. We speak of lower contrast-sensitivity.
Contrast sensitivity can easily be measured in a clinical setting. On the Vistech contrast sensitivity chart there are 5 rows of figures with a line pattern. Each next row has a higher spatial frequency. Each next figure in a row has a lower contrast. Patients are asked to specify the last figure of each row where the line pattern is still visible.
Contrast-sensitivity can be very well measured. This is not so for the next disorder in vision I would like to mention. The consequences of this disorder are hard to imagine.
I am talking of the consequences of pathology of the optic nerve. Often people with pathology like this tell us that they can see what is going on, but the images are fading away. This seems especially the case when there is a lot of information that has to be sent over the optic nerve. I do not know of a method to quantify this phenomenon.
Defects in the occipital lobes of the brain, these are the parts where visual information is processed, can cause problems in recognition. It can be that recognition of letters or words have been lost. But more bizarre forms of loss are possible.
One of my patients, after brain surgery, fails to see whether a face belongs to a male or a female. He can however still recognise familiar faces and knows then if the face belongs to a woman or a man. But the process the other way around is damaged.
So ladies and gentlemen, there are some standardised methods in visual assessment. But not all the visual functions are easily quantified. There is still a lot of ground to cover.
Next, I would like to focus our attention to the technical possibilities available for people with low vision.
I would like to consider illumination first of all.
We have to make a difference between the illumination of the environment and the illumination of tasks that have to be performed.
The level of the illumination of the environment must be normal (300 to 500lux), high (700lux) or low (100lux) depending on the results of the measurements. Special attention has to be paid to the shading of the lamps. Light shining directly in the eyes must be avoided and the areas concerned should be uniformly illuminated. In large rooms neon lightning with well-designed grills is a good choice. For smaller rooms the halogen up-lighters are very practical.
To perform tasks like reading or knitting, a much higher illumination level is required. The level must be 5 to 10 times higher. The earlier mentioned measurements will have given an indication. The recently developed PL lamps (a fluorescence lamp in a smaller form than the neon lamps) are very useful for this purpose. These lamps give an equally illuminated area and produce very little heat; therefore they can be placed quite close to the head. When they are put in position below the eye level the problem of light shining directly in the eyes will not occur. Because of the short distance between the lamp and the paper, the illumination level is high.
At the private homes of the elderly light levels are often too low. The interior design is

mostly dark. Adjustments to these situations are easily suggested, but it can be hard to motivate the elderly to make changes in their familiar environments. Extra lights to do tasks are more easily accepted.

In the resident lounge in nursing homes I spoke of when discussing audiology, the illumination leaves much to be desired. I have been in rooms with neon lighting, where the tubes weren't shielded. Or the fittings of spotlights were used for PL lamps. In both cases light will shine directly in the eyes of the people in that room. The illumination level in these rooms is all right for normal seeing people, but the special needs for people with low vision are not fulfilled. The earlier suggested division in cosy corners not only offers solution to the acoustics, but the illumination requirements could be met as well.

It may be difficult to provide enough light, but it is even more difficult to avoid the high illuminated spots where sunlight enters the room. Sunlight can be very annoying for patients who are oversensitive to light, who have adaptation problems or who have troubles with glare. Sunscreens and lace curtains may help. White lace curtains have to be avoided; they are too bright in sunlight. A living room on the north side of a building should be considered for people who are very sensitive to the sunlight.

One more adjustment can be made in the environment of low vision people.

As you know visual impaired people often have a loss in contrast-sensitivity. They can be helped by the use of extra contrasts. Doors should have sharp contrast to the walls, doorknobs with the doors, light-switches with the walls and so on.

And on a smaller scale too contrasts should be used to their advantage. White plates should be placed on a dark tablecloth. Milk poured in dark coloured cubs, coffee in white ones.

All these adjustments will help people with low vision. It will of course take time and effort to realise them, but when it is done these adaptations are straightforward helpful.

The low vision aids I will introduce to you will give help and have disadvantages. Their helpfulness is always a balance between these two. As with hearing aids, a trial period at home is necessary to learn the outcome of this balance.

After adjusting the illumination conditions magnification can be of help for people with low vision. It is the desired working distance that indicates which optical magnifier can be used. High power reading glasses can be used if a really short working distance is accepted. At a working distance of 10cm objects are seen three times bigger than at the normal reading distance of 30cm. To get a sharp picture on that distance a reading glass with a power of 10 dioptres is necessary.

At a normal reading distance magnification can be obtained with loupes, as long as the needed magnification is not more than 3 times. For this rather low magnification loupes are frequently used. They come in many forms: handheld loupes, loupes mounted on lamps, loupes with build in lamps, loupes mounted on spectacles. Ergonomic arguments will often determine the choice.

When a higher magnification is necessary loupes with higher power are used. They have

shorter working distances and smaller fields of view. These disadvantages make loupes with this high magnification only usable for short time tasks.
When the lower magnification is needed the possibility of enlarging the text should be considered. This bypasses the problem of smaller field of view. The availability of large print is the introduced problem here. Short pieces of text can be enlarged on a photocopier, although at the expense of contrast. Books with enlarged text are available in all Dutch libraries, but I do not know if they are as easily accessible outside the Netherlands.
To bypass the shortened working distance telescopes can be used. Telescopes exist of more than one lens. A 4 up to 6 times magnification at a normal reading distance can be realised by varying the power of the lenses and the distance between those lenses. These telescopes can be handheld or they can be fitted in spectacles.
They too have disadvantages. The field of view is limited, more limited than by using loupes, their depth of field is small and movements of the head are magnified. It is difficult to use telescopes when the control system of head and / or hand movements is diminished.
For the elderly a closed circuit television system (CCTV) is a better solution when magnification of more than 4 times is necessary. With this instrument text can be shifted under a television camera. The image of the text is reproduced on a monitor in front of the reader. With this instrument magnifications up to 30 times are attainable. Moreover the contrast can be enhanced and even reversed. White letters on a dark background give off less illumination than black letters on a white background. There is less light shining in the eyes. Therefore most low vision patients have a preference for reversed contrast.
If a high magnification is used, the text under the television camera has to be shifted regularly. A well-mounted reading table will simplify this, but even then using a CCTV takes a certain amount of skill and effort.
In our visual advice centre three sessions with an occupational therapist are always included when we advise a CCTV.
It is my opinion that CCTV's are the most appropriate reading aids for people with low vision. I learned from a questionnaire that I send to patients half a year after the advice for low vision aids was given however, that my elderly patients can use their CCTV for only 15 minutes at a time.
This means that a CCTV is especially convenient to them for reading short messages such as mail, short articles from the newspaper and other such notices.
For most users reading books by means of a CCTV is not possible. Books on tapes are the better choice here.
Magnifying objects on larger distances can only be achieved by telescopic systems.
Where working distance of 50 to 100cm are required the options are few. Reading music and handicrafts are done at this distance. In reading music every printed detail is important, overview is necessary and often the music has to be played faster than the magnified reading is possible. The solution offered by low vision aids is inadequate.

For handicrafts the field of view of a telescope is small but may provide the required solution. Telescopes are usable beyond the one-meter range. They require steady holding and directing involving strength and stability.

I have come to the last category of aids in low vision. How to shield the eyes from an excess of light out of doors.

A hat to shade the eyes is the best solution in cases of glare. The light used for seeing objects is not diminished. This is important, because people with glare need a high level of illumination.

For those who are oversensitive to light filtering glasses are useful. But not only the light in front, but also from the sides will have to be filtered. There are specially designed shields, which can be worn over the spectacles.

The filters can be made with different absorption characteristics.

Brown filters absorb light of all colours of the spectrum. The absorption can be 50 to 90%.

Coloured filters are used where special frequencies are causing the over sensitivity.

Often blue light causes problems. Yellow or orange filters,are suitable.

It must be kept in mind that these absorbing shields don't improve the visual functions, they only give comfort for over sensitivity.

Let's summarise the subject of low vision.

As in audiology more than one measurement is necessary to describe visual functioning. The smallest visual detail, the field of view, the effect of illumination and the contrast sensitivity are important

The adaptation of illumination is worthwhile. Also the use of contrast can help.

Magnifying aids are available especially for the short distance, for reading. The choice is indicated by the necessary magnification and by ergonomic aspects. A trial period should be part of the selection procedure.

Shields to avoid too much light shining in the eye can give comfort in cases of over sensitivity to light.

We have come a long way already. We know a lot about hearing disability and visual impairment and what technology has to offer in the rehabilitation of either one. Let's now proceed to my last item and consider how to approach impairment when both functions need adjustment. Do you have any questions at this moment, which need answering before we can proceed?

As a low vision specialist I attempt to create a picture of what it means to have a particular form of visual handicap. Information from patients and the results of visual assessment help me to do this. I realise that this picture will never be complete; ever so often, patients will surprise me by sharing aspects of a visual impairment that I had never considered.

When professionally working with hearing impaired patients, we make our own concept of the implications of that handicap. A picture of a combination of vision and hearing handicap presents an unimaginably greater problem then just adding the two problems. I have not yet arrived at a satisfying concept.

I will illustrate this by an encounter I had with a lady.
At that time I worked part of the week as an audiologist and part of the week as a low vision specialist. Occasionally deafblind patients came in for audiology and low vision advice at the same time. I did those consultations in one visit by mutual agreement with the patients. We paid attention first to the audiology questions and secondly to the vision ones.
This lady came to me for advice about a magnifier for reading and a handheld microphone for her hearing aid. During the consultation about the magnifier I noticed at a given moment that I was speaking to her while I was looking for something in the drawer behind her. You can imagine my message was not understood. I apologised and we went on.
20 minutes later we were sitting in another room, discussing the handheld microphone. I wrote a note for her and forgot all I know about contrast. I wrote with a thin blue pen and didn't take care about my handwriting.
This confrontation made me more aware of the extension of the problems in dealing with deafblindness.
An analysis of the interaction between the two disorders provides me with a more structured approach to the problems of this double handicap.
As we already established both hearing and vision have a communicative and a warning function. It has sustained my perception of the problem of deafblindness to put these functions in a matrix. We put the visual communication function, reading, in the upper left cell; the visual warning function, movement detection and overview, in the lower left cell; the auditive communicative function, speech understanding, in the upper right cell and the auditive warning function, the acoustic alarms, in the lower right cell.
We have seen which characteristics in the audiological and visual assessment were informative of the impairment of these functions. So we have an idea which help the technical aids I have mentioned can provide.
We know that besides technical aid, compensation techniques are used to minimise the handicap.
We can put the compensation techniques that use the other sense in a second matrix.
In the upper left cell we see books on tape as a compensation for reading. The sound of a cane, in the lower left cell, is an auditive compensation for mobility problems due to visual impairment. In the upper right cell lip reading is a visual compensation for problems with speech understanding. Light can be used to compensate lost auditive alarming function in the lower left cell.
When there is an auditory as well as a visual disorder, the loss of many of these compensatory mechanisms poses an extra problem. Lost compensations can be put in a third matrix.
The lost compensations are the loss of lip reading in case of an additional visual communication disorder, upper left. The loss of the use of lights as a warning signal in cases of an additional visual loss in warning function, lower left. The uselessness of books

on tape in case of an additional hearing impairment, upper right and the loss of the ability to hear the cane in case of an additional hearing loss, lower left.
In assisting patients with a double handicap, it is important to check to which extent the 'normal' compensatory mechanisms can still be employed. It can very well be that those mechanisms need support. Extra lighting to improve lip-reading. Connecting the cassette player to a hearing aid for listening to the book on tape.
I summarised the most important steps on slides.
Assessment of auditory and visual functions is necessary to be able to apply technical solutions.
A trial period is necessary before prescribing a low vision aid or hearing aid.
Adjustments of the environment are as important as the prescribing of personal aids.
Technical aids are mainly developed to improve the communication function.
However the warning function should not be forgotten.
Rehabilitation of deafblind patients should be structured by means of the matrix of lost compensations.
Information of the two sensory systems should be available and interpreted.
Co-operation / teamwork with an advice centre specialised in the other sensory impairment is necessary.
There is one more daily life encounter I would like to share with you.
This patient in his early seventies suffers from tunnel vision and very bad speech understanding. Training in outside mobility was the rehabilitation target at that moment. The training in walking with a cane was done by an occupational therapist.
The patient was wearing two hearing aids. We were convinced that this was the appropriate fitting. The loss in the visual warning function, due to the tunnel vision, was optimally compensated for by this.
However the occupational therapist reported that the rehabilitation target, independent mobility, could not be reached. So for outside mobility the patient stayed dependent on a companion. For the communication between these two the hearing aid fitting wasn't optimal. A handheld microphone was a better solution for this.
I have learned from this case that although the impairment in one sense is sufficiently accommodated by technical aids the need to accommodate the impairment in the other sense (or the impossibility of this) can indicate a revaluation of the technical aids.
This is the essence of my experience with the elderly deafblind and I would like to offer this to you as a guideline in all efforts to improve on the quality of life of deafblind people.
Ladies and gentlemen, I thank you.

REHABILITATION OF THE HEARING-VISUALLY IMPAIRED IN THE NETHERLANDS

Sita Schipper (The Netherlands)

The rehabilitation of elderly hearing-visually impaired is mainly done by regional institutions for visually impaired people. I work at Theofaan, a rehabilitation centre for visually impaired in the south of the Netherlands. Theofaan has four centres in the south. Since 1989, Theofaan also takes care of the hearing-visually impaired, most of them elderly people. The rehabilitation is paid for by the government.

Every regional centre for visually impaired and hearing-visually impaired has three departments: children, adults and information.

For the audiological part we cooperate with the specialised audiological centres.

Everything I have said above and will say in this lecture is about the way of working in my own regional centre. I know that there are differences in the way of working with the hearing-visually impaired in the Netherlands, but I think the main line will be just the same.

When an elderly person gets visually impaired, he can ask for assistance from a rehabilitation centre for the visually impaired. His ophthalmologist can ask for assistance especially for low-vision examination. Referral from ophthalmologists are given easily and correctly. It is also possible that a family doctor advises his patient to contact us. When the visually impaired person had contact with other social helpers (e.g. homecare) then referral from them is also possible. The first contact is mostly by telephone. At that moment it is not always clear whether the person is hearing impaired as well. Sometimes, the audiological centre refers a client to us. It rarely happens that an ear specialist refers his hearing-visually impaired patient to us.

Rehabilitation of hearing-visually impaired elderly persons is not yet very well-known to doctors, family doctors and the hearing-visually impaired themselves. People do not expect the knowledge of this combination of handicaps in a centre for rehabilitation of visually impaired people.

Hearing this and receiving the information about the importance of regarding the visual and hearing impairment as a whole is a surprise in the first contact with client.

Also hearing-visually impaired people who live in a serviceflat or a nursing home can be considered for rehabilitation. The staff of these homes can refer as well.

This was the case of Mrs. A. The head of the floor where she lived called us with to ask whether there were possibilities for recreational activities. Mrs. A. had already tried

spoken lecture, but she did not like it. It appeared she could not understand it and needed technical hearing aids.

One of the important characteristics of our rehabilitation model is that it is question-oriented. We focus on the questions of the client, but sometimes it takes some time before the client formulates them. We are not, in the first place, telling the client everything we can offer him, so that he can "choose". Of course we give him (general) information about Theofaan.

My experience is that especially for most of the elderly hearing-visually impaired it is difficult to say what they want, even more difficult than it is for the elderly visually impaired. My theory about this phenomenon is that the elderly hearing-visually impaired already had so many disappointments because of their hearing-vision limitations that they do not dare to believe in improvement of their situation. A remedy for this can be to start with rehabilitation in a small way and work from success to success.

In the beginning of the contact with the client or his representative, we are always asking for permission for calling in the medical details, at least vision and hearing, sometimes (in another stage) neurological, for instance, as well.

When those medical details have arrived, we discuss the clients question and medical details in a multidisciplinary team (social worker, rehabilitation therapist, low-vision worker, psychologist, information worker). In two places in the Netherlands, a one-year experiment is carried out, in working together with different institutions for the deafblind. With their permission the elderly hearing-visually impaired are subject of discussion in this "inter-institutional team". The purpose of these discussions is to get to know what organisation and which discipline has to make the first investigation.

The first (life) contact with the hearing-visually impaired usually takes place at his own home. The specialised rehabilitation therapist, or the social worker, or both, visit the client. The purpose of this contact is to collect information about what the client wants and what he feels are his limitations. Acquiring information from his network, his partner, children, nurses etc. about his aids, and what he experiences as a lack of aids. And of course, the client obtains more information about the rehabilitation institute and its rehabilitation possibilities. Together with the client, we formulate his goals and how we think we can achieve them. Sometimes it is not known before the first visit that the client is also hearing impaired. The specialised rehabilitation worker is not yet involved at that moment, but called in as soon as possible.

An investigation of the client's problems is made. For example in the field of psycho-social problems: dealing with the lost, social contacts, communication and the changing of the life-role. And the practical problems in the field of activities of day-to-day living, to handling the low-vision and hearing aids, mobility, material needs, recreational activities, etc. Much attention is also paid to which technical aids are available and what is still needed.

Mrs. B. is a widow of 80 years old. She lives on her own in a little village. She has one

hearing aid, and she can read with her TV magnifier. One of her questions was going to the supermarket. With mobility training and better hearing aids she could manage this by herself again.

The worker discusses the now formulated questions of the hearing-visually impaired client in a multidisciplinary team. The medical details are discussed, if necessary appointments for low-vision and audiological assessments are made, and perhaps for contact with other disciplines. The goals the client wants to achieve are also discussed.

Most of the clients get a low-vision examination in the regional centre, the low-vision specialist takes account of the hearing problems of the client. The most suitable low-vision aid, ranging from magnifying glass to TV loupe to sunglasses and illumination, is selected. The client can try out the low-vision aid at his own home. When it gives the desired result, the insurance company will pay for it. The client also gets personal advice about illumination in his own house.

Mr. C. gets a magnifier on a stand. He is instructed how to read and write with this aid, and there is also attention to his posture.

The audiological examination takes place in a specialised centre, from another organisation. Usually, the therapist of Theofaan sends a letter with some information about the hearing-visual problems of the client to the audiology centre. The audiological information resulting from the examination is sent to the rehabilitation centre. The hearing aids are partially paid by the insurance company. The client receives his low-vision and hearing aids, the therapist of Theofaan starts the instruction of how to use them. The possibilities for the hearing-visually impaired of acting independently varies from person to person.

The rehabilitation can take place at home, but also at the regional centre, individually or in a group. The choice of location depends on the following reasons: the physical condition of the client, his psychological condition, the kind of questions (mobility training takes always place at home) etc. The communication problems do not form a reason for choosing individual rehabilitation. However, rehabilitation in a group demands a small group, about four to six hearing-visually impaired elderly people, and good supervision. The presence of other hearing-visually impaired is stimulating for both the psycho-social and the practical rehabilitation.

In Eindhoven, discussion (therapy) groups were held for elderly hearing-visually impaired people. The program consists of 10 meetings and the topics include how can I tell other people what I see and hear, asking for help and how to handle lack of understanding.

In the first meeting (and repeated in several other meetings), the hearing aids (hearing loop, hear-it) are introduced and a number of discussion rules as well (speaking one at a time, speaking slow and clear, asking for repetition, etc.). It appeared that even in contact with fellow-sufferers these rules are very difficult.

It is also possible to discuss these and other subjects individually with a social worker, such as how to handle the loss and the social contacts. The role in society has changed

very much for the hearing-visually impaired elderly person and rehabilitation is a help in finding a new balance. The network of a hearing-visually impaired elderly person has often become very small and many elderly persons are not able to build a new network. In rehabilitation, much attention is paid to this problem. It is important that everyone in the present network learns about the hearing-vision handicap and learns how to communicate with the hearing-visually impaired person. Often, it is necessary that the network is enlarged, e.g. with special educated volunteers, or in some cases with peripatetic workers from Kalorama. They can also keep an eye on the network when the rehabilitation has finished.

Communication is always a topic in rehabilitation. Of course, it is possible to learn special communication methods like handspelling, Lorm, 4-hands sign language, but most of the elderly hearing-visually impaired do not need these methods. In most situations, it is possible to communicate orally or by writing, even sometimes with the help of the TV magnifier. For communication, it is also very important that the elderly hearing-visually impaired person becomes aware of what is the right communication for him and insists that everyone communicates in this way. But this assertiveness is very difficult to achieve for the elderly and therefore it is even more important to educate the network.

Concerning the practical problems, it is possible to learn, within the limits of the client, all kind of activities of day-to-day life (including cooking), mobility, recreational activities (learning an appropriate hobby), but also braille or using a PC. We pay attention to perception training. Very important is that the elderly client becomes aware of what he still sees, hears, feels, smells. This training is useful for total rehabilitation.

Mrs. D. suffers a lot from headaches. When she is doing her housework, she has a looking distance of 10 cm. Every task tires her very much. In the perception training she learns to feel, and she acquires confidence in what she is doing without using her vision.

In my opinion, almost all rehabilitation subjects are possible for the elderly, in an adapted pace and with the necessary repetition. Extra stimulation for acquiring new experiences is important, especially at the beginning of rehabilitation.

Rehabilitation is a period in the life of a hearing-visually impaired elderly person. In this period, he gets social support, learns practical skills and learns to give his handicap a place in his life. But after this rehabilitation, he might need continued support and help. On a small scale, Kalorama can give help at present. There are more or less concrete plans to give more support to elderly hearing-visually impaired people. This should be a co-operation between several institutions working for the hearing-visually impaired and should consist of an opportunity to meet fellow sufferers, to combat the lack of daily information and to signal deterioration of hearing and seeing.

Jan Prickarts (The Netherlands)

Kalorama has developed several initiatives in working with older people with acquired deafblindness.
In our institution 64 residents live in eight groups. Of these, three groups (each 8 persons) are suited for older residents (over 70 years), with lifelong double sensory handicaps or deafblindness acquired on old age.
In the latter cases deafblindness is often accompanied by psychiatric or psycho-geriatric symptoms.
In peripatetic work Kalorama also offers services for older deafblind at Kalorama, at their own home, in nursing-homes, both directed at the clients themselves and at their social environment - professional and non-professional.
Our approach for the deafblind in general - regardless of age / severity of hearing and visual loss / age when handicaps start - can be summarised with some keywords.
In this lecture I want to show that these keywords can also be applied for the specific group under consideration at this conference.
First I shall refer to the general approach of Kalorama; second I want to show in 2 case-descriptions how this approach can be applied for this specific group.
In Kalorama's general approach two tracks can be noticed.
In practice these tracks interfere with each other.
A. Developmental Rehabilitation
In training or education of people with more or less definable abilities we try to follow programmed routing, e.g. learning of new communication skills to overcome communication problems and non-access to information-sources, mobility and orientation instruction, and training of household-activities.
We try to agree about time-schedule, goals to achieve etc.
While training we are willing to follow the client in changing demands and 'rebuild' our program following these new directions.
Often abilities are learned without explicit goals or routes how to achieve them.
B. Functioning-oriented Rehabilitation
We try to offer an environment which enables clients themselves to protect and influence their quality of life.
In our institute this is done by offering a direct accessible broad social and physical environment with possibilities for functioning according to personal standards.
It is possible to engage in household activities, to engage in courses, several forms of spending leisure-time [illegible] to go to work.
To avoid 'well-m[illegible]' interference by us as professionals, opportunities are offered in an inviting broad and rich environment out of which the resident chooses her or his favourable chances for functioning.
The client is free to 'move about', he is free to engage in activities, try them, go on with

them, drop, try again, switch over to something completely new, stick to old-fashioned way of doing things, etc.
The only evaluation criterion should be the appreciation of the situation by the resident himself: 'Is this contributing to my Quality of Life?, 'Is this contributing to a pleasant, good, happy, safe existence?'
We see Quality of Life (QOL) as a quality of the interaction between the individual and his environment.
To enhance QOL we, as professionals, are oriented on the environment.
We are to bring into view for residents opportunities,

- uncovering already present ones but forgotten, bring again into view,
- thinking of new ones,
- guarantee adequate support, not to much, not to little,
- give structure when necessary,
- give information, not to much, not to little.

In peripatetic work for clients at their homes or in nursing homes our support can be seen as a combination of both forms of rehabilitation.
Efforts are made to head for QOL by:

- optimising communication skills and information gathering,
- being a source of information,
- creating new chances for functioning, draw upon sources, stimulate to take up old hobbies,
- being a source for functioning.

We seek to match the social talents and possibilities of the peripatetic worker and characteristics of the client. We ask ourselves: which worker can be successful in bringing a client to functioning?
How can one see if our approach works, in other words: if there is 'Quality of life' ?
In recent literature dealing with rehabilitation and QOL one can find listings of aspects, domains of importance, which can contribute to QOL.
Often mentioned are:

- health and security
- social network , social support
- feeling of autonomy
- reduction of illnesses / limitations: developmental rehabilitation.
- occupation of roles

In common sense one speaks of QOL if all these features are optimised, often according to social standards.
At Kalorama we are aiming at optimising these features, while understanding that the balance of these aspects, the priority in contributing to QOL, is specific for each individual.

Therefore:

- all aspects don't need to be favourably fulfilled,
- all aspects don't ask for professional intervention.

In one case: optimising communication means a lot to QOL, in the other case this is not enough, in another case QOL is guaranteed without.

In our approach social abilities (e.g. 'independence', 'assertiveness' or 'acceptance of handicaps') should not be learned in training or in programmed routes. Social learning is an automatic process which takes place in interaction with the environment.

This does not mean that professional care or support is not needed.

For old clients with acquired deafblindness QOL often IS AT RISK. For them it is often difficult to maintain an acceptable level of QOL.

The issue is how to facilitate natural psychological processes of coping, mourning, acceptance without interference by giving advice or guidelines about manner or speed of these processes.

We try to do so by 'building' an environment in which these processes happen in a natural manner.

In this environment we appeal primarily and most importantly to the healthy part of a persons pattern of functioning.

In this sense we are also interested in whether and how training of new abilities contribute to 'Quality of life'.

Rehabilitation should not be oriented on minimising limitations per se or learning new skills per se.

Professional intervention starts when there is an expectation that it will contribute to QOL, and this is needed because natural mechanisms fail to do so (temporarily).

Professional intervention can start with a concrete demand of the client, which soon can change to other demands.

When possible we start, without arguing or understanding the rationality of the demand, or even when we find it unrealistic.

More important is that we see if our offer is or will be contributing to QOL.

Referring to the list, which I mentioned before one can say:

- "without reduction of illnesses, QOL is possible!"
- "without acceptance of handicaps, QOL is possible!"
- "without developmental rehabilitation, QOL is possible!"

In Kalorama's view:

- "without favourable circumstances QOL is not possible!"

For improving QOL

Rehabilitation which is oriented on functioning is more important than

Rehabilitation which is oriented on development or training.

For improving QOL

Rehabilitation which is oriented on the environment and is directed by subjective

standards of clients is more important than
Rehabilitation which is oriented on compensating for limitations and the development of specific behaviour.
Kalorama looks at more subjective standards to evaluate this approach: Ultimately QOL is a subjective matter.
The client himself is the only one who can determine whether something is contributing to his QOL, to his feelings of wellbeing.
Fortunately QOL is accomplished in an implicit, nonconscious learning process by reacting to favourable circumstances.
In our view we trust on a "natural regulation":
Individuals "approach" circumstances which contribute to QOL, mostly without thinking how this works.
In the same way circumstances are dropped and avoided which don't contribute to QOL.
So clients can be trusted the mechanisms of choosing implicitly their favourable circumstances.
For older people with acquired deafblindness circumstances can change, fade away, can loose their attractiveness and accessibility, complaints arise and dominate above the healthy part of a persons pattern of functioning:
QOL is at risk, this is the point where professional intervention starts.
How we try to regain QOL I want to show in a few case descriptions.
Mrs. B is 79 years old and lives at Kalorama since two years. She is severely visual handicapped since her twenties and got hard of hearing in the last years. Before coming to Kalorama she lived in a nursing home. This home referred to Kalorama because of the problems they had with her, wandering through the home at night, screaming that strange men were threatening her. It was difficult to inform her about activities because of her growing memory problems. Most of the time she was alone in her room, where she sometimes picked up knitting socks. Family visited her everyday, which she enjoyed very much.
Kalorama proposed a removal to our home, to a specific group of older deafblind with psycho-geriatric problems. Because she had to wait for a place in our institute, the nursing home decided a temporary stay in a psychiatric ward in a general hospital.
She now lives at Kalorama in a group which is suited for older residents (most over 80), with psycho-geriatric symptoms.
All residents have their own bedroom. Most time of the day all 8 residents are in the living room, in which at least one professional is available. In our approach we are oriented on the functioning of these residents, avoiding implicitly disorientation. In this environment circumstances are offered, e.g. homely-activities, which are easily recognised and don't appeal to vulnerable memory-processes. Residents get involved or attracted ("that soup smells good") or even take action, e.g. in preparing dinner.
Staff are trained to deal with communicative features due to combined sensory limitations

and with psycho-geriatric symptoms.
Deafblindness on old age often comes with other disabilities. In psychological literature one speaks of "multiple vulnerability".
In old age one has to cope with different loss-experiences: loss of partner, relatives and friends, loss of physical abilities.
Other symptoms arise: geronto-psychiatric or psycho-geriatric.
Cumulative loss-experiences affect a person's flexibility, ability to re-adjust, redirect ones focus towards new circumstances or old forgotten ones. Often this takes place in a natural regulation, in which QOL is maintained or regained without professional intervention.
Adequate social support is often a strong predictor for healthy adaptation.
Most older clients with acquired deafblindness we see (are referred to us) have accompanying problems. In some cases deafblindness is the core handicap, e.g. responsible for a (temporary) mood disturbance. In other cases deafblindness and e.g. dementia have no causal relationship, but influence each other negatively.
Mrs. G is 86 years old and lives in a nursing-home since three years. In her best ear there is a slight hearing loss. Recently she became severely disabled in both eyes, which had a further negative influence on her communicative skills.
The nursing home referred to Kalorama for help for the communication problems they had with Mrs. G. They noticed that she was unhappy and could not be stimulated to take part in activities in the home.
A peripatetic worker started visiting Mrs. G one year ago.
She had no demands, except for the difficulties with reading her watch and tuning her favourite radio stations. The worker proposed concrete solutions to these problems, which worked out.
After that, in weekly visits, Mrs. G told him that she was lonely but refused to take part in social activities. She was afraid of being put in a position where she could not refuse or withdraw at the moment she wanted. Because of her vision loss, she could not leave alone. The worker proposed to accompany her and guaranteed "escape" when she asked for it. After two joint visits, she engaged in one weekly social event, which she soon learned to visit on her own.
The worker is still visiting her, reads the newspaper to her and takes her out for a walk. In the meantime he wrote a list with important guidelines for communicating with Mrs. G., and is looking for a volunteer who can take over his weekly visits.
We notice that old people with acquired deafblindness whom we contact, in most cases lack accessibility to appropriate information and communication channels.
Older deafblind live in their own houses or in nursing homes, often isolated, without favourable circumstances.
Our recommendation is that in many cases, clients would profit from being offering a meeting point, e.g. a living room in a nursing home, where they could meet other people, other clients with deafblindness and get information and support from professionals.

qualified in communication methods and bringing clients to function, improving QOL.
For Quality of Life :
Rehabilitation oriented on functioning is more important than
Rehabilitation oriented on development (education & training)
Quality of Life :
quality of the interaction between the individual and his/her environment.
Professional support is environment-oriented.
Quality of Life is experienced by the client.
His/her appreciation of QOL is the possible starting point for professional support and its evaluation.
Constructional behaviour analysis:

- oriented on functioning
- not on complaints
- oriented on environment
- not on behaviour
- oriented on learning
- not on unlearning

Kalorama approach :
Quality of Life as experienced by the client :
guideline for professional support.
Environment-oriented :

- offering optimal space for individual life-style
- offering broad social & physical environment with possibilities for functioning to personal standards (= contributing to QOL).

COMMUNICATION WORKSHOP

Liz Duncan (United Kingdom) and Martha Bagley (USA)

Questions were answered from the earlier Plenary session on communication. The first question concerned how to deal with requests for help from nursing homes for older individuals who have lost their vision and hearing and are no longer able to receive communication and how early intervention might make that situation better. Another question involved the application of communication techniques used with congenitally deafblind to older adults. In response to another question the presenter asserted that activity is important to older deafblind adults, as without it and social contact what do they have to communicate about? A question was asked about deafblind people living on their own and how they manage that.

What followed was a brief discussion about the development of a communication system that utilises raised letters. Two versions of this system were presented along with a discussion of how it would be used.

Communication
Systems and Tools
Auditory Communication

- Assistive Listening Devices
- Hearing Aids
- Cochlea Implants

Visual Communication

- Sign Language
- Print
- Speech Reading

Tactile Communication

- Print on Palm
- Sign Language
- Braille
- Raised Letters
- Objects
- One Hand Manual Alphabet (finger spelling).

SURVEY OF 281 OLD PERSONS AND THEIR PRACTICAL, EMOTIONAL AND EXISTENTIAL NEEDS

Ann Svensson (Sweden)

In this workshop I will present a doctoral thesis in social work made in 1990 by a Swedish researcher: Ojan Thoreaus Olsson, called: "After 80, a study of older people's requirements for social care, and of their care situations." (Report of social work no. 48, University of Stockholm), 1990.

The purposes of the study were to describe the needs of older people from their own perspective and to see how those needs were met or why they were not met.

The study has nothing to do with deafblindness but is utterly useful for the understanding of old people's way of thinking, their life-situations, difficulties and problems that they meet during the ageing process.

I will not focus on the methods of the qualitative study or how the analyses were made, which is very clearly described in the thesis, but what I find is more relevant at present are the results.

We who are not there yet, who are not 80 or over, have probably a lot of preconceived apprehensions about old people, their situations, needs and problems. BUT what do they really think, feel, dream about, and what do they really want and need from us in our roles as daughters, sons, grandchildren, relatives, neighbours, friends or professionals?

This study answers some of those questions since the researcher interviewed 281 old people in order to get a deeper knowledge of their life-situation, problems and needs from their own point of view.

The author chose the ages 80 and over since earlier studies and statistics had shown that there is an important increase of physical and mental problems between the ages of 75-80, and as a result of this, the need for care increases. In this age group the numbers of widows and widowers goes up as their spouses die, resulting in the possibilities of receiving care from them ending.

The study was made as a total investigation of all people of this age group, who lived in their own homes, not in old people's homes or other institutions, in three areas: a rural, a suburban and an inner-city area.

After a pilot study the author could identify three major categories of needs:

- Practical needs
- Emotional needs
- Existential needs

PRACTICAL NEEDS

I will describe the results in this field very briefly since most of you who attend this workshop are well acquainted with these needs.
Though most of the respondents were quite content with the practical care they got, there are some interesting differences between the three living areas and between men and women.
In the rural area the interviewees had a greater need of help than in the other two areas. They lived further away from shops and services. Some had houses that were not modernised and quite a few needed help with heavy tasks such as chopping firewood, clearing away with snow, gardening etc.
The group of people who expressed no lack of practical help were the married men. They were well cared for by their wives. The group who reported needs that were not met by anyone were married women. Men who became widowers experienced a greater loss concerning practical matters than women whose men died. This could be explained by the fact that women of those generations are used to doing the practical work in the home and felt a greater responsibility for that kind of work, and also that the women were generally younger than their husbands. The children tended to care more for a widowed parent than for parents who both were still alive and the formal care services seemed to give priority to single people.

EMOTIONAL NEEDS

According to the author it was not as easy to categorise the emotional problems as the practical. They were not easily discovered and the respondents had difficulties in finding words to describe them. It was not natural for so many to ask for help concerning these matters.
In the pilot study three major emotional difficulties were discovered:

- feelings of anxiety and insecurity
- feelings of insignificance and of being neglected
- feelings of sorrow and grief

In this field there were also some interesting differences between single people and married people and between men and women. The single people lacked this care more than did the married people. Most wives and husbands gave each other this care at least to some extent. Men lacked emotional support more than women. Reasons for this could be that it is generally easier for women to talk about emotions. It was easier for women to find a substituting care system when their spouses or closest friends died. Women more than men are the bearers of social relations, also concerning the relations with the children. Men tended to know their children through their wives while women had closer contact with the children. This did not so often change when the wife died.

Feelings of anxiety and insecurity:
According to earlier research older people tend to worry about ageing and it's consequences, to be struck by illness, pain and death and to be victims of crime. Other sources of anxiety could be practical, like problems in the physical environment, and emotional, like loneliness.
Many expressed feelings of insecurity because of a decreased ability to control different kinds of life-situations; fear of getting a severe memory loss such as forgetting time and place, going out and not being able to find the way back, or putting away money or other things and not finding them again; fear of odd behaviours such as going to parties or other gatherings and being shaky in the hands, spilling the coffee or having problems with incontinence, or giving wrong answers to questions; fear of not getting adequate help such as not knowing when the home-help would come and who it would be; fear of radically changed circumstances of life such as having to move away from home, or losing the partner and friends etc. As a result of those fears many tended to isolate themselves, not leaving their homes.
To have someone who could give advice was important for the feelings of security; advice in such matters as discussing finances, discussing the significance of symptoms of illness, interpreting letters or messages from authorities, making decisions about repairing household machines, cars etc.
Most of the 281 respondents had someone who could give them advice, mainly from their own families, relatives or friends. They even turned to them concerning problems where professionals had more knowledge. If they became ill they asked some relative or friend for advice before they went to the medical caregivers.
Feelings of insignificance and of being neglected:
Earlier reports showed that these are areas of great importance for aged people. Some say that if they don't mean anything to anyone they might as well be dead. It is easier for people to maintain their self-respect and belief in their own capability if they are well integrated with their social environment, if they are significant to other people and if they feel that help of different kinds are expected from them.
Unfortunately there is less need in today's society for old people and a negative process might take place when an individual loose his professional role or other roles because of age. Together with unclear expectations the old person becomes more dependant upon the attitudes towards him from people around. If those attitudes are negative he might identify himself in negative terms.
In this study approximately half of the respondents often described themselves as being neglected, pushed aside and a burden for other people. The other half found great joy in the fact that they actually were asked for by other people.
Many of the respondents wanted to give help to other people; practical help, emotional support or advice. Most common was to support others with practical help. Not many had anyone who asked them for emotional support which is a bit difficult to understand since

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old people often have a lot of time to spend listening to others. Hardly any younger, children or others asked old persons for advice. Professionals never asked for practical help, emotional support or advice.

Feelings of sorrow and grief:

These feelings are very common during the ageing process since most old people experience that their spouses, sisters, brothers, other relatives or friends die. How this affect their life-situations depends on the support or lack of support they get from the social environment.

-One of the people interviewed, a man who was 90 years, had lost his wife, his three sons, his four brothers and two sisters, all his other relatives and all his old friends. There was only the daughter left.

Statistics in Sweden shows that between the years of 80 and 84, approximately 80% of women and 40% of men has lost their spouses.

There is some research being done about how the loss of a spouse affects young and middle-aged people but there is very little knowledge of what effects it has on older people.

One study reports that the loneliness that widows and widowers experience after their spouse's death affects them much more severely than the isolation those that lived a single life felt.

There is also an increased risk that they would die as a result of the loss. Those deaths are mostly related to heart diseases, accidents or suicides.

The support from the social environment was of great importance for the mourning process. Most of them who had lost someone close to them needed to communicate and to verbalise their thoughts and feelings, especially if there were feelings of guilt towards the one who had died.

There was again a difference between men and women. Men had less close friends outside marriage and even if they had some friends their relations were not of such a close and intimate kind as between husband and wife and between female friends. Some of the women even increased their social interactions after the death of the husband.

Quite a few had difficulties with other people's attitudes towards their grief process. As if the fact that it is "natural" for death among older peo[illegible] would reduce the strength of their sorrow. This might be a reason why old people don't get enough support when they are left alone.

A few said that it was a relief when their spouse died. In all those cases the spouse had been severely ill for a long time, and the practical and mental burden for the other person was very difficult to carry.

The children but also friends and relatives had important roles as caregivers in those situations. No one of the respondents had talked with anyone from the home-help services about their sorrows. Priests and others employed within the church was considered as important caregivers.

EXISTENTIAL NEEDS

- To find a meaning in life from now until death
- To find a meaning with life as a whole and to be able to contribute with one's own knowledge and experiences
- To prepare for your own death

To find a meaning in life from now until death:
Many of the respondents felt dissatisfied with contemporary life. Now, when they had lost spouse, friends and relatives and/or the capability of doing useful things, life had less meaning than it had before. All of those who thought that life still had meaning were busy with work or other occupations related to their capacity. Some felt that life was meaningful as long as they could be together with people they liked.
Those who thought present life had no meaning all expressed that they were waiting for death to come and those who still found meaning in life did not want to die.
Earlier research confirms that a meaningful life is highly correlated to close relationships and to usefulness.
To find a meaning with life as a whole and to be able to contribute with one's own knowledge and experiences:
The author was well acquainted with the fact that old people often wanted to talk about their lives and about times gone by. She found that this had an important purpose for the respondents; to evaluate and sum up their lives when they felt that death was coming closer.
Quite a few of the people interviewed were documenting their lives. Some wrote about their lives themselves, some had their life-stories recorded. Some expressed that they would like to document their lives but they didn't know how.
To prepare for your own death:
Most of the respondents reported that they were preparing for their deaths, emotionally and practically, but few had anyone with whom they could share this.
Concerning the existential needs, almost everyone that had someone to talk with said that they were mainly of the same age group and lifestyle as themselves. More seldom it was possible to talk with younger relatives or friends and practically never with the formal caregivers except for people employed by the church.

INTERNATIONAL AWARENESS CAMPAIGN

Anneke Balder (The Netherlands)

- This is a brainstorming session
- Anneke will be guiding us and she needs no further introduction as she is one of the motors behind this meeting
- We have not had time to co-ordinate our discussion and maybe that is not necessary in this type of meeting
- Anneke and her group have worked extremely hard to get the question of acquired deafblindness on all the appropriate agendas of organisations and networks and groups concerned with deafblindness
- WE feel the time is ripe for a more structural approach to make the needs of elderly people known and in particular the effects of sensory impairment on this group.
- We should discuss today which approach or activities we should adopt or recommend
- Can what is going on in our countries be unified in a more global way?
- It seems from personal experience that when one discusses older people one tends to discuss more their functional needs and capabilities than their communication possibilities and potential. They are considered as being old without a previous life. When looking at the questionnaires from services destined for this population practically nothing is asked of the individuals sensory status
- What organisations at a Euro-international level should be made aware and what is the best procedure for this awareness which should, at least theoretically, be an easy touch as it concerns each and everyone one of us.
- What can we do in our own country to lobby for this group?
- Anneke has some thoughts but please feel free to comment at all times
- All suggestions will be taken into consideration and certainly followed up by the Acquired Deafblindness Network.

The following points were made during the group discussion that followed:

- Terminology i.e. deafblind is not readily applicable to the elderly group.
- Needs to be a move away from medical focus into functioning and mainstreaming, addressing and understanding sensory needs.
- Who are we trying to educate, who is our target audience?
- Denmark has had an awareness campaign for the past 2 years using video, TV and other publicity material. Now it is beginning to see results.
- Is it the responsibility of the Network to undertake this?

- Huge numbers of people are affected by this – resource implications (700 per 100,000 – Finland).
- These huge numbers mean that there may be a different model of service delivery i.e. more local.
- Why do we need this campaign?
- The Acquired Deafblindness Network could contribute to a campaign, but not organise it.
- Target geriatricians?
- Who are the natural partners – Age-Link Europe etc..
- Statistics – Governments will naturally seek their own, however, statistics are only part of the picture, governments must understand the implications of any level of combined hearing and vision loss.
- Functional definition.
- Create services to attract or find people.
- A multi-dimensional approach.
- Elderly lobby and association of professionals could have much influence and impact.
- Question of identities, the elderly are a multifaceted group.
- Perhaps an information pack?
- The routes and contacts needed will vary from country to country.
- A film to raise awareness.
- Co-operation vision and hearing professionals need to be aware and understand each others services.
- Action at a national level, enabled by the Acquired Deafblindness Network, who could provide information and awareness at a Euro-political level.
- Try to get some comparables at a Euro-level.

CONFIDENT LIVING PROGRAM A COMMUNITY BASED LEARNING EXPERIENCE FOR OLDER ADULTS WITH VISION AND/OR HEARING LOSSES

Matina Bagley (USA)

The Confident Living Program is a structured learning experience provided in a group setting for people over 60 with vision and/or hearing losses. It was designed and developed in response to the following problems:

- Increase in population as age rises
- Fragmentation of services
- Reduced resources of older adults
- One more loss
- Lack of understanding among caregivers & family
- Differing service delivery philosophies (medical – social).

The Confident Living Program curriculum includes modules on the eye, the ear, coping with vision loss, coping with hearing loss, and coping skills. These units contain basic information and are not designed to take the place of the rehabilitation specialist, but to inform the consumer about the service possibilities that exist. A question was asked about whether group members who did not have a hearing loss, for example, were interested in that topic. A discussion followed of strategies for insuring full participation.

The Confident Living Program addresses the participants informational, social and emotional needs. Although the program was designed to meet informational needs the social and emotional are just as important. The added benefit can be gained from a group that bonds together. The role of the group facilitator is to provide information and support the bonding process.

The Confident Living Program provides participants with a safe place to raise concerns and problems. All communications are confidential. Communication is facilitated as needed and there are people there who want to listen.

The Confident Living Program materials (a facilitator and participant Manual) are available from the Helen Keller National Centre, 111 Middle Neck Rd., Sands Point, NY 11050, 516-944-8900.

HOME INSRUCTORS, A PROGRAMME IN SWEDEN

Anita Bengtsson and Margaretha Lagerdahl (Sweden)

First of all I will tell you that I'm so happy to be here in your lovely country of Italy.
My name is Mrs. Anita Bengtsson. I come from a little town, called Halmstad on the west coast of Sweden. Halmstad has about 86.000 inhabitants. In the summer we have many visitors, because we have nice beaches just outside the town. But I think the water at home is colder than here in Italy!
In Sweden service and support to disabled people is an important concern for society. The responsibility is shared between the state, the county council and the local authorities.
The state institutes laws and is responsible for General Insurance – for example pensions and sickness benefit. The state is also responsible for many measures concerning disabled people and the labour market. The state has also a special organisation for deafblind people. The county is divided into in 11 regions with a deafblind consultant in each region.
The County Council is responsible for Health and Medical service, included habilitation and rehabilitation and even technical aids. The County Council also organise and finance interpreters for those with hearing impairments.
The third level is the municipality and it is at this level that I'm working. The main aim with the municipality social services is to enable disabled persons to participate in society and to live on equal terms as other individuals. Later I will tell you about some of the support and services that disabled people can have from the municipality.
My profession is Home-instructor for low vision, blind and deafblind people. In my work with deafblind people, I co-operated with the deafblind consultant from the state as I mentioned to you before. In Sweden we are about 350 Home-instructors at the municipality level. The visual impaired and deafblind do not need to pay for help from home-instructors.
To work with old deafblind people will take a long time. In the beginning it's very important just to sit down and listen to them. Before you can really start to support your client, you must create contact and a feeling of confidence in them. During the opening conversation, I'm also trying to get a picture of the problems for the person who is sitting in front of me.
It's important to remember that every person is unique. So you cannot treat them all in the same way. In this case it is very important that the relatives are involved in the rehabilitation process.
One of our missions is to train the deafblind in ADL. We are working with primary ADL. This includes activities in connection with:

- mealtime
- hygiene
- dressing
- mobility
- communication - with Braille - manual alphabet.

Taking care of yourself is very important for self-confidence and integrity.
We are also working on the way the deafblind person is living and leisure time. In this is included:

- preparation of food
- how to take care of the clothes
- how to clean up
- how to go to the nearby shop.

The aim is that the deafblind person should be able to stay in their usual environment and keep their social relations.
As I said before it is the County Council which is responsible for the technical aids. The County Council has two different departments that we can co-operate with. They are called The Sight-Centre and the Hearing-Aids-Centre. From these offices, my clients get their technical aids and they have also some training on how they can use them.
My mission is to take over the training with the aids in their own homes.
Becoming isolated is a risk for many deafblind people. Therefore it s a task for me to help them to be more active. It's important that the client themselves tells me what they want to do, what they can do and which activities are meaningful for them.
It's a question not just of keeping former activities, but also of finding new activities which are adapted for deafblind people.
We also try to motivate people to take part in other rehabilitation activities for example weeks-rehabilitation in adult education college, where they have specially courses for deafblind people. If you are interesting in these courses, I have some prospectuses with me.
We also try to motivate deafblind people to go to study circles, and to have contact with the organisation for deafblind people and also with the organisation for visually impaired people.
We also have group-activities. In the groups there are 5 - 6 persons. The participants are training together and have to meet other people in the same situation. For many of them, this meeting is very successful.
We have also special groups who work with pottery. It's a good activity for both blind and deafblind people.
Especially for young people, we have groups where we discuss what kind of clothes to wear and what you can do to be more pretty and handsome. A very popular group activity

is cooking. Sometimes we have separate groups for men and women, and there is a competition to see who can do the best dinner.
As a deafblind person, you need information about several things in society. It's not only taking care of yourselves in your home. It's my mission to inform people about all the support and service in society and to help the client to make contact with the responsible persons in society.
Support and services for deafblind people could for example be:

Communication service
Disabled persons who can't go by public transports are allowed to take a taxi or an adapted bus. The fee in Halmstad is the same as public transport. If you need to have a guide, when you go out to different activities, you can have a person from the social services with you without any cost. You can even get a personal assistant who can help you with different things in daily living. But then you must be totally deafblind and not more then 65 years old.
It's much more usual that the deafblind people gets a Home Help Service. Home help is given to persons who need personal and practical help to enable them to live in their own home and to live an active and independent life.
Deaf-blind people can also be given financial aid from local authorities to adapt their homes. If they want, they can also move to special services apartments, where you can have contact with staff 24 hours.
There is also other work you have to do as a Home-instructor that is not so well known. It can be for example to have contact with the department responsible for streets about pavements, and even with the park department to talk about trees and shrubbery hanging out over the pavement.
I think that my job as a Home-instructor can give a better quality of life for many elderly people.
But if I am to help them, we must have contact with each other. Therefore it is important that I inform staff in the social services and the medical/health systems about my work. I can do this with a leaflet, but the best way is to go to different staff groups and inform them directly. It must be quite natural for them to contact the Home-instructor when they meet deafblind people in their work. It's also very important that the social and health care staff develop a better knowledge of deafblindness so they do not confuse these problems over seeing and hearing with senility.
The Home-instructor is a good investment for society. Through my job I teach many visual impaired and deaf-blind people to take care of themselves. So they don't need so much help from society.
In this way, society saves a lot of money. But the most important thing with my job is that I can help visual impaired and deafblind people to have a better life.

INFORMATION PROVISION AND NON-SPECIALIST TRAINING

Ole E. Mortensen (Denmark)

First of all, let us be clear about who we mean when we say "non-specialists". This term can apply to a great number of people. In my presentation I have chosen to focus on professionals who get in some kind of contact with elderly people with acquired deafblindness, but who don't know much (or anything) about deafblindness and maybe even aren't aware that such a condition exists. They may be home helpers, nurses, staff at homes for the elderly and others who work with elderly people.

Providing actual training and education in deafblindness is practically impossible for the larger part of this group. These professionals are too scattered geographically, there are too many of them, and deafblind people constitute too small a part of their work – it is simply too expensive for their employers.

Therefore the way to reach them is through information. The aims of information for this group may be:

- Raise awareness
- Provide background information
- Provide practical skills
- Make changes in receiver's approach to working with deafblind people
- Show how to access specialists
- Not to make the receiver into a specialist

In this first part of this morning's plenary I will discuss a few aspects related to information for non-specialists – and how to overcome them. This will be a rough outline – a picture painted with a broad brush. I will not be presenting the universal truth about information for non-specialists, and some of you may have other ideas about information. But although I will only be scratching the surface, I will present a few pointers which in my opinion may hold true in many cases.

The process of information can be viewed like this (in a simple illustration). These are the stages that the receiver must go through in order for the information to be a success. Or in other words, these are the stages where the information can go wrong and make you miss your point.

1. Exposure
2. Initial attention
3. Continued attention

4. Understanding
   - Linguistic understanding
   - Cognitive understanding of the contents (on the basis of knowledge about related topics)
   - Acceptance of the message
5. Memorising (saving)
   - Storage of understanding and acceptance
   - Retrieval of understanding and acceptance in the actual situation
   - Decision of action on the basis of the understanding and acceptance
6. Change or strengthening of action

I will focus on the first three points for several reasons:
- there isn't time to go through them all in detail (although they are all relevant and interesting)
- there are some interesting and relevant general points to be made about them
- they are the precondition for the rest of the process to be successful.

Exposure:

First precondition for reaching your target audience with the information is exposing them to the information. This may seem overly simple and basic, but it is an important point that has to be carefully considered. If they don't get in contact with the information, it doesn't matter how well it has been planned and produced.

In this plenary we focus on information that reaches the receiver when the sender isn't there at the same time, i.e. typically printed information. Therefore we have to consider the way we distribute the information products.

We have to ask questions such as:

When does the information reach the target audience? What will they be doing when they are exposed to it – reading their professional magazine, watching TV, reading the newspaper, going through their mail at the job, doing their work or what? This is important for their readiness to receive information. If they are busy doing something else, it may take more to turn their attention to the information product.

If it is printed material, we must consider how to put it into the hands of the receiver. By mail directly to him? By having someone give it to him? By having him order it from you? By making him pick it up somewhere?

If it is an article or a poster, we must make sure to put it somewhere we know the target audience will be reading/watching. What papers and magazines do they read? Where do they go? And what will they be thinking about at that time. It is no coincidence that we find posters and other material about health issues (for instance about quitting to smoke) in the doctor's waiting room.

Can we make the receiver active in getting the material by ordering it himself? If he

hears/reads about our interesting material and decides to order it, he will be active in getting exposed to the material, which will make him more alert to it when it arrives, and help us in getting his attention.

Initial attention

When we have made sure that our target audience will be exposed to the material, the next important step is to make him pay attention to it. We all know that it is possible to see something and not pay any attention to it. Seeing isn't the same as noticing.

We live in a society with a great information overload. We are exposed to so much information, that it is impossible to pay attention to it all. We therefore choose among the offers for information as receivers. As senders it means that our information is in great competition with other information products.

This is especially true for a target audience such as our non-specialist, who don't know much about deafblindness or even are aware of its existence. This means that they don't realise that there are things that they need to know – they have a latent information need. They have no prior interest in the subject.

This makes them harder to get in touch with.

If we are interested in a subject, we are hungry for any information on this subject, no matter how inaccessible it is. The manual for our new computer or car or sewing machine or model air plane may be printed in small letters in bad print, but we want to read it anyway.

So we have to get their attention to make them willing to invest time and mental resources in our information.

What makes people interested? Well, if we don't trust their interest in elderly deafblindness to be enough, we must make our information interesting and appealing in another way.

One way is to make it stand out. If it is a booklet or a folder that we are exposing the target audience to, one solution might be to make the cover interesting in format, colour, layout etc. Now, there may be some of you who think that this important subject shouldn't be degraded to colours and layout. But my point is very pragmatic. We must consider what works with the target audience and follow that in order for our information to get through.

Let me give you an example which you all may know from your own countries. Let us look at the ads in a Danish newspaper concerning removals. A lot of ads, so if you were a removal company, how would you make your ad stand out? We create a snappy headline that is certain to make potential customers (for who else will be reading these ads?) take notice. "FLYTTE GRATIS – kan vi ikke, men..." In English: "FREE REMOVALS – we can't offer, but..."

A problem with snappy headlines, nice layouts and bright colours may be that we will not be the only ones using that to get attention. Look at these ads again. There are quite a few using the same snappy headline, which diminishes the effect.

Let me give you an example from our own area. The Information Centre for Acquired Deafblindness were part of a group producing a booklet with advice for home helpers who work with elderly people with a vision impairment, a hearing impairment or a combination of both. This information was sent to all home helpers in the country. This layout and colours should make them keep their interest long enough to start reading the text.
Tomorrow in the plenary on the United Nations' Standard Rules, Kirsten Jansbol also from the Information Centre for Acquired Deafblindness will tell more about this particular information initiative.
Furthermore, this booklet was handed to them by their superior with a request that they read it. This helps initial attention very much, when the material is given to the receiver by someone he trusts or who is in the position to order him to read it. Just that fact that it comes from a side where you are used to expecting interesting and relevant information rubs off on this information as well and make the receiver expect something interesting and relevant again.
Another example: Advice for hospital staff (particularly nurses) on good communication with patients who have a vision and/or hearing impairment. Handed out by the head of the hospital ward, hopefully with a request that it was read, but also appealing to look at to boost interest.
Another example: A poster informing that there is something called deafblindness and that more information about it can be had at the HKNC. Interesting layout, an almost completely black very large illustration with very little text, and a play on words referring to the colour of the poster.
The appealing look of printed material may carry importance also beyond attracting the initial attention. If the look of the information material generates a positive feeling in the receiver this attitude will stay while beginning to read the text. This makes the receiver ready to invest time and mental resources into understanding the text.

With this we go into the third stage:

Continued attention.
Our receiver has been exposed to the material. It has caught his initial attention. Now he opens the material and starts to read the text. If the text isn't able to keep his attention, he will put it aside and that is the end of that.
What is important for making him continue to pay attention? Well, there has been a lot of research into audience reception of information and communication during the last 15 years, and it is now clear that the receiver plays a very active and important part in the information process. Earlier the receiver was regarded as an empty cup – and some of us maybe even more empty than others – just waiting to be filled with information. This

theory was later named the injection theory, where information was injected into the heads of passive receivers.

With the realisation of the receiver being an active participant, we also realise that it is his interests and knowledge that controls what he receives. Two people who watch the same TV-program doesn't see the same program. Their understanding and construction of the program bear many similarities, but there are also important differences. This is very interesting, but I won't be able to go further into this.

And how does this apply for our efforts to keep our receiver's attention? Well, if he doesn't find that reading the text will have a positive result in the end, he won't read on. Two typical positive results may be that he finds it entertaining, or that he finds it relevant for him in some way. He can find it relevant for his work, for him as a person, as a man, as a user of the language, as someone who will be making a booklet himself one of these days and therefore need input on how to do it – or how not to do it – and so on.

It is only the receiver who decide if this material will fulfil a need or a wish in him. Now, we know that our information about elderly deafblind people is very relevant for our target audience – although they don't know it yet themselves. We must therefore try and convince our receiver that this is relevant for him – believe it or not. And we must do so fast, so that he may read the rest of the material in that light.

There are two sides to this kind of relevance:

1. We must make the receiver understand that elderly deafblind people exist, and that he may very likely come in contact with them, or even be in contact with them already. The information is relevant for him as a professional who wants to do his job as best he can.
2. In order to do this, we must explain very quickly what age-related deafblindness means. He needs this information to be able to understand what else we tell him, and first and foremost that he may be in contact with elderly deafblind people already without having realised it.

We can't just use the phrase elderly deafblind and suppose that our target audience will know what we talk about. Previous knowledge is a precondition for cognitive understanding. You have to know something in advance in order to learn something new. All new information is being understood on the basis of what you know already. Our receiver may have no previous knowledge on the subject deafblindness, or even have an inaccurate knowledge so that when he sees the word deafblind, he thinks "Helen Keller". In this case our information effort will probably fail.

Let me finish be showing you a few examples from our own information work that illustrates how we try to overcome the problem, that when you communicate to people without any prior knowledge or understanding of the subject, you have to make some things clear right from the start, because it is necessary for the continued attention and for the next stages in the process.

I hope this short introduction to some basic considerations when planning information to non-specialists has given you some inspiration for your own work. There is much more to be said but we will save that for another time. Thank you for listening.

STAFF DEVELOPMENT

Lucette Teurlings (The Netherlands)

It gives me great pleasure to have the opportunity to talk to you about employee training. I have called my talk :"When is training more than just learning?" Or in a different way: "when is learning more than just training?"

But first let me introduce myself. My name is Lucette Teurlings and I am an educational specialist in the field of organisational psychology; here I am representing two organisations in The Netherlands. I am involved with policy making in the field of personnel and organisation with Sonneheerdt, a national centre for the partially-sighted and the blind in The Netherlands. With nearly 400 employees, Sonneheerdt has considerable expertise in the fields of supported living, vocational training and employment advising, industrial employment, cultural activities, creativity development and holiday resorts. A small percentage of our clients are deaf as well as blind.

In addition, I am the educational co-ordinator for OBT courses, the educational bureau of the OBT, the seven nursing homes for partially-sighted and blind elderly people in The Netherlands. The percentage of deafblind people in these nursing homes is many times greater – about 20%. The subject of my discourse now is the training of staff and the teaching methods that result in the maximum possible effect from the training.

What is training?

For me, training is a part of the total organisational policy. In my view, when we talk about training policy, we are not considering the training of individual employees to occupy different or higher positions or because as a manager you want to give your employee a present: 'you may follow a course'. Training policy, therefore, does not form part of the social policy of the organisation.

Why is training a part of the total organisational policy?

Organisations strive to achieve certain goals; they have formulated these as a vision, a mission and as policy goals. To carry out this mission the employees must perform certain tasks for which they need a particular level of knowledge and skill. If they do not satisfy these functional requirements, training can provide the means by which they can be offered the opportunity to gain the knowledge and experience they need. If your organisation supports the idea of providing an optimum service for the deafblind then all the co-workers need to be able to communicate with the clients. They must, for example, be able to use sign language. If they can't do this, then there is a need for training. The staff must learn it. Teaching this skill forms a part of the training policy of your organisation.

What is the difference between training and learning?

When we hear the term training we tend to think of course rooms, difficult lessons, school

desks and a teacher standing in front of the class. The employee is not at work for a few days because he or she 'is on a course'. When he or she returns there is a pile of work waiting and the intentions, formulated during the course, are quickly forgotten because of the pressure of every-day activities. After six months you happen to find the course book by accident and with a feeling of nostalgia you remember the pleasant days that you spent with your fellow course members. That really was a very good course! I am sure that most of you recognise the situation. It was a good course, you learned a lot, the trainers were pleasant and you took part in a lot of exercises, but what you learned you have not put into practice.

What is the problem?

In fact, it can have little result in the working situation if you, as the only employee in the organisation, follow a course outside the organisation. I give you two reasons why it doesn't work:

1. Training and learning aren't equal.
2. You can learn in your working situation, without training in a traditional way.

I will explain my theses.

1. It is a misconception that learning is much the same as buying-in objective knowledge from outside. "Send employees on a course, then all our problems will be solved". But gaining knowledge is more than just sitting in the classroom for a few days and listening to someone telling you how things should actually be done. And knowledge means here more than the theory from the books. It is the knowledge of knowing how to act in different practical situations.
   Every individual must continually acquire new knowledge in an active manner. This happens in stages: understanding, translating into practice and applying and finding solutions for new problems that arise on the basis of the knowledge you have acquired.
2. I explain my second thesis: a good deal of knowledge is already present in the organisation. Why then should you send your people on a course? A better solution would be to search out the so-called knowledge repositories and to give them the opportunity to spread that knowledge. In this way you create both formal and informal learning situations: Mentor-coach systems, work discussions, supervision, internal discussion with colleagues not directly involved, operational discussions, internal training and quality projects. These 'ordinary' parts of the work are seldom seen in relation to training. It is quite inspiring to make use of these work forms for the learning goal. Working is learning and learning is working!

The difference between knowing and doing

I always speak of knowledge and skills in the same breath. In our lives we have all learned a great deal. But possessing knowledge says nothing about its application. That we have

certain skills that we do not use may be because we do not want to or because we can't. In the Netherlands we all know how to cycle. It doesn't mean that we all do: some people use there cars for a two-minute drive. It's not because they don't know how to cycle; it is because they don't want to.

If there is something you can't do, you need to learn the skill. First in a protected learning environment and later in a practical situation. (All children learn from their parents how to cycle. The parents teach them in the backyard, in a square, and later in the normal street.) If there is something that we don't want to do then we are confronted with a motivation problem. And unfortunately, training is not the solution for unmotivated people. (In The Netherlands we don't need to teach adults how to cycle. The government tells us about the pollution and the senselessness of driving a car for a two minute ride.) Sending someone on a course because they have already thrown in the towel is a waste of time. People can only motivate themselves. The best that the management can do is to create the optimum conditions.

In addition to knowledge and skills, the learning process must pay a great deal of attention to 'demeanour' and 'attitude'. This is a very difficult area but is also essential in our professional field: the service industry. A colleague of mine always talks about 'experience through living it'. You need (and this can only be for a short time) to experience personally what it is like to be deafblind and not know who is standing next to you, not know where you can put down the glass of beer that has just been handed to you during a party, not know whether what you have said has been understood. This provides insight and it is an experience that has a better learning effect than reading books about the problems that the deafblind are confronted with.

My colleague Annemarieke Meelker at the OBT educational bureau has developed a course package for the elderly deafblind at the instigation of the Dutch Deafblind Foundation and which I am going to introduce to you in the workshop this afternoon. The aforesaid elements are embodied in this course package.

Conclusion

Of course I don't want to throw all training overboard. It makes a sound and important contribution, but can only be effective if we take account of the aspects I have already touched on.

Transfer

The second part of my talk is about transfer.

An important final reason for the minimal effect of training is the lack of transfer or possibilities for implementation. Transfer implies having the capacity and the willingness to apply the knowledge and the skills learned in the training programme in the work situation and the habit of doing this. Because people still always learn through training, I want to spend a bit more time on this aspect of the subject.

With the transfer of training there are a number of people who should be mentioned: in

the first and most important place is the trainer. He or she is responsible for carrying out the training instructions. These can, for example, be: 'to develop a training programme for new employees so that within a month they are in a position to communicate with the deafblind clients of our organisation'. Others involved are the members of the management team. They are in a position to give instructions to the trainer but they remain responsible for providing a good service to their clients. The immediate supervisors, the trainee and the colleagues are involved when it concerns daily work in practice, during the communication with the deafblind client.

This brings me to three factors that promote the transfer.

- Internal consistency: this is a specialist term for a very logical question: with the current training programme are we achieving the goal we are aiming for, are we solving the hiatus that exists between the current skills and the skills we need and is the training method suitable for the skills to be learned and for the participants?
- External consistency: is the training situation as much like the working situation as possible? Are all those involved in agreement concerning the way that training will be carried out? External consistency is so important because the learning processes that take place in and around the daily work are far more powerful than those that take place as a result of a course and which are completed in a course room.
- Finally, the persons I have mentioned as being involved: the supervisors, the colleagues and the trainee himself or herself but now formulated in a different way: the working environment of the trainee, are of the greatest importance for the transfer. Related aspects that I can name are: the interest of the team, optimum co-operation, the provision of opportunities for feedback and for practice. When the trainee comes to the working environment from the course for 'communication with deafblind clients' and does not get the opportunity from the supervisors to put into practice what has been learned, then what has been learned will quickly be lost.

We have all experienced these situations. Skill and speed are soon lost if you can't practice them every day. The interest of your team in what you have learned is essential if you are going to risk making errors. A culture in which errors are punished is fatal for the learning process. Barbara Streisand sings: 'there are no mistakes, just lessons to be learnt'. If you as managers or as supervisors are successful in creating such a learning climate you can save much of the expense of external training!

Finally, I hope that my talk has contributed something to your picture of the role of training in organisations. So training is more than just learning. For all of us the challenge is to give it form. Of course it's the same with this seminar. It's not a present from our managers. We have the responsibility to tell them about our experiences.

I wish you and your colleagues success in the organisations in which you are working.

Thank you all for your attention.

"CONSTRUCTIONAL BEHAVIOUR ANALYSIS AND THE KALORAMA APPROACH"

Jan Prickarts (The Netherlands)

At Kalorama there is an explicit approach in which are formulated guidelines about how to support clients. Principles have their origin in a psychotherapeutical approach which is called "constructional behavioural analysis". This form of psychotherapy is also practised at our institution.

First I shall briefly introduce this therapy and its translation into the Kalorama approach. Next, to make this workshop a workshop, I want to give some case descriptions and ask for your reactions to them.

In general, psychotherapy is about helping clients to get rid of their psychological complaints (e.g. depression, anxiety, psychosomatic problems). In this approach this is not achieved by elimination of causes which lead to complaints, or disconnecting reinforcement mechanisms which control and maintain complaints (e.g. (cognitive) self-control, approval or disapproval of behaviour).

Although, in this therapy there is some respect for complaints. In CBA-theory, complaints have a temporary constructive function which guarantees a minimal existential solution. They fill emptiness, which is even more (life-)threatening for the individual. In therapy complaints are not analysed. Only its function is recognised. Clients are given the opportunity to talk about their complaints, if they would like to.

Therapeutic energy is mainly directed towards the healthy part of a clients way of living, his pattern of functioning. The client is asked to look back on recent, concrete moments and is invited to talk about his doing and not-doing - which is reacting to the environment - and to relate this to his feelings of well-being.

In therapy a learning process starts. The client is put back on his specific functioning pattern.

The focus of the client is directed outward, away from his complaints.

After some time this focus gets strong enough to maintain outside the therapy sessions.

This process is self-reinforcing, and needs no reinforcement from "outside" (i.e. by the therapist). There is no interference (approval or disapproval) about what a client does or does not. Advice, solutions for problems are strictly not given. Reinforcing by the therapist of a clients actions are not necessary.

So, in this approach aspects, which lead to healthy functioning, are reinforced naturally. This approach is about learning, not about unlearning.

When the healthy part of a persons functioning-pattern has become strong enough (in an implicit learning process), the constructive function of complaints becomes superfluous and complaints disappear.
They have not to be unlearned, or focussed on.
At Kalorama these therapeutic principles are translated into an approach to supporting clients who live in our institute. This is done by offering a direct accessible broad social and physical environment with possibilities for functioning according to personal standards.
Kalorama looks at more subjective standards to evaluate this approach :
Ultimately QOL is a subjective matter.

Cases workshop

Mrs. B, 82 years old, lives in her own house.
Last year she acquired deafblindness very rapidly.
Because of her deafblindness she has withdrawn from social activities she used to join. As a volunteer she visited older people in her neighbourhood.
Nowadays she spends most of her time sitting in her chair without starting activities. She gets help from her family who brings her meal everyday.
'I am too handicapped to have a pleasant life'.
Her GP, who thinks she is depressive, told her to meet other deaf or blind people, so she could work on her handicaps.
'You are the only one who can change your position!'

Questions:

Do you agree with the statement of the GP?
Are there other options to help Mrs. B?
Mrs. H , 83 years came to our institution two years ago.
She never was not married and always lived very independently form others.
She had been deafblind for 15 years and learned new ways of house-keeping.
She had a heart failure and because of the worsening of her physical state it became more and more impossible for her to take care of herself.
Family and doctor had to convince her that it would be better if she moved to a home where could be taken care of.
She consented with a bad grace and came to Kalorama, to a group with seven other older deafblind persons.
She has only a little contact with one other resident and more contact with a few professional workers, who she trusts.
Despite our approach of giving optimal space for her wishes and giving opportunities for functioning (e.g. she likes to talk about her life abroad and talking about world-news, she kept a small botanical garden) she was complaining about the care she received.

At a moment the refused to take her medication. Omitting it a few weeks could be life-threatening.
Because her worsening physical state it was thought that it would be better
to move her to another group with staff ,more specialised in handling accompanying physical care.
Management decided on the removal, although she was believed not to consent.

Questions:
Do you think that the autonomy (right to decide for her own life) has been respected ?
What about her refusal to take mediation ?
How should the management decision be conveyed to her ?
Mr. A lives in a nursing home, in which he is the only deafblind person.
He was moved to this home after some dangerous situations at his home.
There was an incident in which a neighbour was just in time to put out a fire because of a forgotten burning cigar.
He was wandering at night, screaming for help.
Because of communication problems he was moved on the same day he was informed about the removal.
In the home there is a strong suspicion of memory problems, which seem to worsen because of the great lack of appropriate stimulation.
It is difficult to find suitable activities.

Questions:
What help could be given to this person (and/ or to his environment) ?
What diagnostic information is needed to start help ?

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TRAINING OF NON-SPECIALISTS: A TRAINING PACKAGE IN THE NETHERLANDS

Lucette Teurlings (The Netherlands)

For who?
The training package is developed for workers in homes for the elderly.

The educational aims are:
- To recognise the changes in behaviour
- To use the scheme to increase recognition of elderly deafblindness
- To recognise the problems
- To know the specific needs
- To develop a basic attitude

Subjects in the package:
- What is your own experience with the subject and what is the problem?
- How to recognise elderly deafblindness
- Psycho-social functioning
- Communication and information
- Orientation and mobility
- Reflection and image forming
- Making a care plan

The method of working:
- Becoming aware (some theory)
- Raising consciousness (discussion)
- Becoming experienced (practice)

Content of the reader:
- Psycho-social functioning
- Communication and information
- Orientation and mobility
- Daily living and leisure interests

How much time?
Time needed for the lectures:

The first meeting takes three hours, the second (about two weeks later) takes 90 minutes. People are recommended to read the reader before the first meeting.

For more information:
Stichting Doof-Blinden
P. O. Box 222
Q. 3500 AE UTRECHT
The Netherlands
Telephone: +31 30 276 99 70
Fax: +31 30 271 28 92
E-mail: sdg@wxs.nl

SENSE IN DERBYSHIRE OUTREACH DEVELOPMENT PROJECT FOR OLDER PEOPLE WITH ACQUIRED DEAFBLINDNESS

"Assessing and meeting the needs of Older Sensory Impaired People"

Sarah Goodwin (UK)

The Project

Reason for Being

Following the publication of the Good Practice Guidelines 'Think Dual Sensory', a commitment to examine and develop services to meet the needs of Older people with acquired Deafblindness developed in Derbyshire amongst the service providers.

Time scale

September 1996 – August 1999

Location

Southern half of Derbyshire

Funding

Joint funding from Southern Derbyshire Health Authority, Derbyshire County Social Services, Derby City Social Services and Sense

Management

Steering Group of the above with local voluntary organisations (Disability Direct, Derbyshire Centre for Integrated Living, Derbyshire Association for the Blind and Campaign for Tackling Acquired Deafness)

Development Worker line managed through Sense

Structure

In depth study of 6 Older people

Aims

1. The detailing of the need for better provision
2. The development of existing sensory services
3. The setting up of new services
4. Deafblind people's access to general services

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5. A blue print for securing specialist services for deafblind people

Programme Focus Areas

1. Raise awareness of the needs of deafblind people
2. Audit current services
3. Identify, locate and consult with deafblind people, their carers and families
4. Undertake specialist assessments of individuals
5. Develop specialist services to meet these needs by developing a strategy for implementation, assessment and care management, and training and resource implications
6. Improve the access of deafblind people to the wide range of general social welfare, health care and community services
7. Develop a strategy for securing the services developed

Outcomes

Activities

Local definitions and identification of needs

Incidence Data	Research Registration
Increased Awareness	Formal training Presence Contacts
Improved Practice	Joint Visits Assessment Skills training Liaison Advocacy
Review of existing services	Recommendations Support

Efficient provision of Aids and Adaptations

Services

Development Worker	Service Review Service Development

Human Aids	Communicator Guide Intervenor Guide Help
Residential	Respite Homes for Life
Resource Centre	Information/ Advice Assessment for Aids
Peer Groups	Integrated, Deafblind and Front Room
Rehabilitation	Programmes for Daily Living and Mobility
Family Support	Education, skills training &Counselling

Definition of Terms

The concept of need is referred to as something within us which drives us to achieve some purpose or attain some emotional / physical necessity (Payne, 1991, in Modern Social Work Theory). 'Need' is construed officially as the requirements of the individual to enable them to achieve, maintain or restore an acceptable level of social independence or quality of life, as defined by a particular care agency or authority DoH (1991 – Care management and Assessment). Need is a personal concept as no two people define or perceive it in the same way. Need can be defined as felt, expressed or prescribed by professional, normative (set standards) or comparative need (who is or is not receiving already). A level of personal adaptation is expected as need is based on personal and not structural deficiencies.

Seven needs (accommodation, domestic/ personal assistance, health, counselling/information, social life /employment /education, finance and transport - with arguments around whether communication should be a particular need or an underpinning principle) had been identified by Disabled people in Derbyshire and continue to be used. Unofficially but in reality, these have been pared down even further for older people to a focus on warmth, cleanliness and nutrition.

The assessment process identifies particular needs and therefore ensures some direction to the response each different individual receives, whether to take account of personal preference, avoiding unnecessary input or rationing services only for particular levels of need. In order for assessment to be completed effectively there should be some degree of user participation and on going sharing of information and problem solving. Current

restrictions around workload and limitations of understanding of the importance of this process compromise it's effectiveness.

Barriers to Assessment of Older Deafblind People

Attitudes towards ageing

The negative connotations of ageing (arising from fear and denigration of the process and associations with decline and decay) affect the perspectives of professionals and Older people themselves. Stereotypes and assumptions regarding needs (eg. for protection) and competence limit appraisal and reduce encouragement to achieve true potential.

Also the Older person's behaviour within that process is stereotyped as grateful and accepting. Limited expectations of what can be achieved through the process also affect the range of possible outcomes suggested or fought for.

There is no yardstick of norms for ageing unlike for child development so Older people tend to pick up and confirm societal perceptions, portrayed in clothing and behaviour, resulting in overly limited roles.

Carers/family wishes

Some Older people have already been written off by their own families or other support mechanisms who then struggle to see the point of further contact which seems only to tire or distress the individual. It may also interfere with the established roles and expectations that people have taken on, where further change will be uncomfortable on top of other 'adjustments and sacrifices' already made.

Carers are subject to the stereotypes of society and so tend to focus on and fight for services catering only for physical needs – ignoring the holistic approach to meeting needs.

Motivation to participate

Many Older people may have other illnesses or have been through similar processes with no benefit. This results in fatigue and lack of motivation to participate. Those with a dual sensory loss may also struggle with actual mental and physical tiredness due to the energy and concentration required to communicate. Some Older people do not define themselves as being Deafblind or in need and see their difficulties only as part of the ageing process for which there is no cure. Professionals are guilty of colluding with this notion where support is withheld because, for instance, the limited time equipment or services may be used for.

Formality of process

Expectations of the assessment process being brief, one way and with the limited involvement of the Older person, pervade. Many professionals do not explain the reason for assessment or ensure that this is fully understood by the individual. Duplication by individual services also results in 'assessment fatigue' and lack of participation.

Documentation tends to be overly brief and constraining or time consuming with excessive and irrelevant questions. Pertinent questions are also determined by expectation and stereotypes, resulting in, for example, the exclusion of the issue of sexuality.
More attention is required in following up assessments to identify changing circumstances and killing the notion that it is a one off task. Further deterioration in either sight or hearing, if the person has dual sensory loss, can result in a strategy change as fundamental as communication mode.
Clarifying needs v's wants is important but at the same time being creative and open minded in terms of needs and possible options in spite of the issues of age and dual sensory loss. Many of the needs will not be around the traditional physical areas but around accessing information, communication and mobility. Finding ways of expressing these needs is required to emphasise the fundamental nature of the difficulties and the positive impact that addressing them could have on the individual's mental health and independence. It should be as acceptable to request a Communicator Guide as, for instance, requesting meals on wheels.

Involvement
Emphasis on effective involvement in the process is minimal with little time or effort put into empowerment and finding ways of giving the individual control. More accessible information is needed about the potential of the assessment process for improving quality of life. Also access to the final documentation is problematic for those with a dual sensory loss. There must be more effort put into providing copies of records on tape, in braille and in other accessible mediums.

Communication
Those assessing Older people with a dual sensory loss will need to spend considerably longer ensuring that the assessment is completed adequately. With this group relationship building is essential, not only to ensure trust and to enable the person to share relevant personal information, but also to ensure that communication can occur with ease. Without visual and auditory clues, it becomes much more difficult for an individual to interact and develop rapport.
There may be profound emotional distress due to the dual loss which the individual may have difficulty recognising, and expressing. This must be taken into consideration by anyone making assessments of this group.
An additional Illness/Disability can complicate communication, for instance the impact of arthritis on manual communication or braille reading, and the difficulties created by dementia adding to the confusion created by sight and hearing problems.

Conclusions
The professional assessing may end up in reality with several roles including advocate, interpreter and teacher. Appropriate supervision and support is required to ensure that the

impact of this can be reduced.
An effective assessment process is costly in terms of time, effort and skilled professionals but this input should balance out given that there should be fewer emergency referrals, less inappropriate placements and greater value added in terms of quality of life improvements for the individuals.

Overcoming Barriers to Assessment

Barrier	Strategy
Carers / Family attitudes	Carers / Family attitudes
Assumption of lack of or inappropriate Service Reponses	Development of Appropriate Services Increase awareness of support possibilities
Orevious Assessment Experiences	Clarification of Assessment role, format and Deafblind person's participation
Unwillingness to participate due to psychological withdrawal, physical illness or general fatigue	Perseverance Peer Group contact Sensitivity to tiredness and reduce Contact times Use good practice in all approaches
Sensitivity around collection of personal information	Collect and provide information in accessible formats
Difficult communication	Building a relationship and being evreative to establish an effective system

Creativity and Responsiveness Throgh Assessment

Current	Assessment	Future
Day Centres, Deaf and Blind groups	*	Deafblind Groups and Front Room Day Care
Residential Care, Home Care Aides	*	Communicator Guides Smaller Group Living
Meals on wheels	*	Adult Education supported cookery Courses Mobility training
Bingo, talks and sleeping	*	Aromatherapy Tactile and scent reminiscence Food and Drink tasting Tactile dominoes
Specialist CCW Aids and Adaptations assessment and provision	*	Sensory Environment Unit with Specialist Workers in Dual Sensory loss and Equipment technicians

Final Thoughts.....

Definitions and Legitimacy

The battle continues to define this group as Deafblind, despite personal attitudes around disability and labelling, and as requiring appropriate services in order to challenge ageist assumptions and avoid creating invisible recipients. The tension between morbidity, mortality and low incidence as opposed to the effort required to assess, identify or develop services and encourage participation by the older person can be too much.

Concept of Need....

Care must be taken to avoid the concept of need becoming disabling – where people are seen as being 'in need' rather than as having rights to resources in order to enable them to continue to participate in society

Negative v's Positive Aspects of Need

The delicate balance of presenting assessments of need which emphasise the negative aspects of an individual's life and therefore achieve funding v's challenging stereotypes and building upon skills and positive life aspects continues.

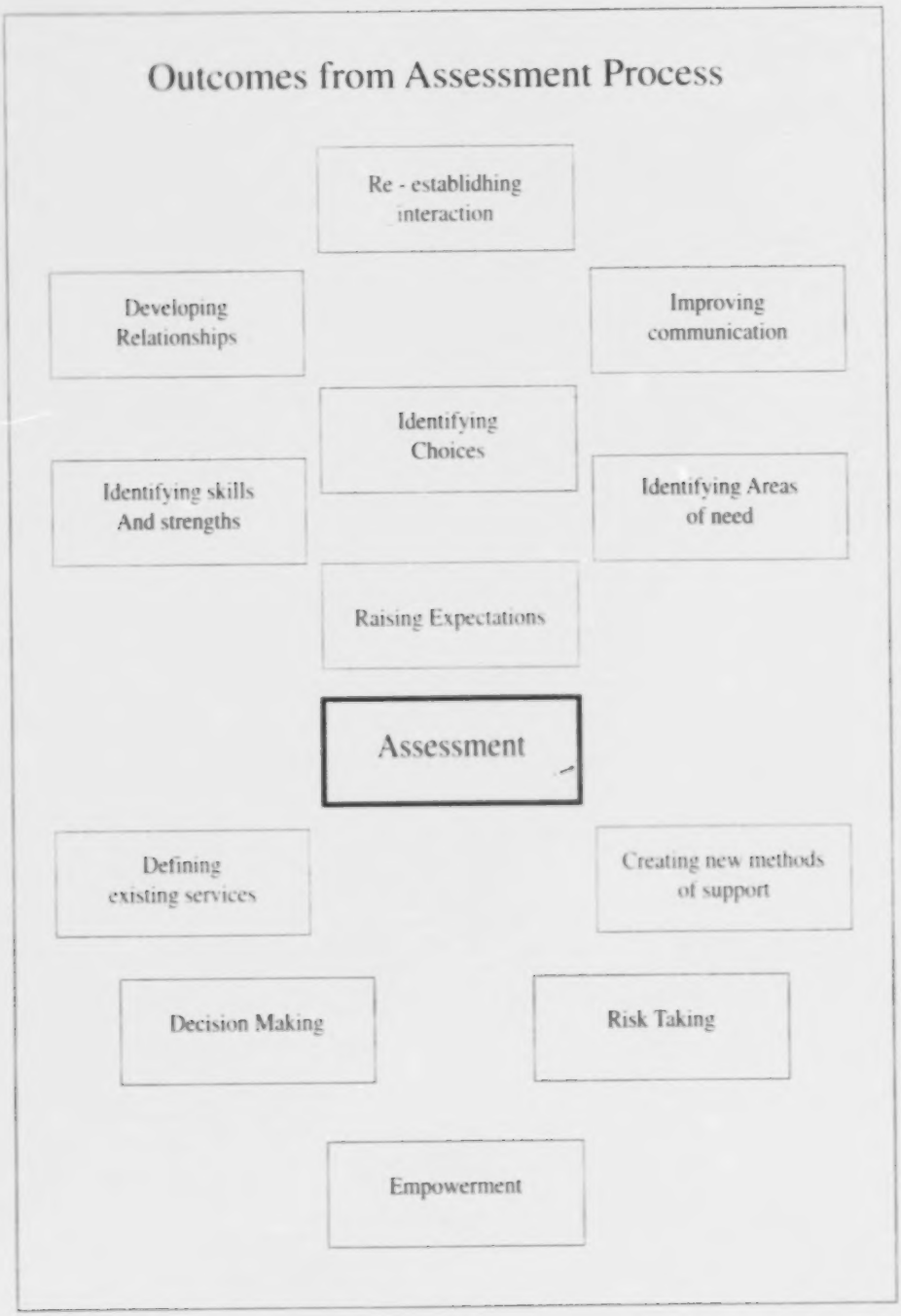
Assessment of Potential

Assessments of potential to achieve and expectations of rehabilitation, learning and development must be more consciously and effectively built in.

Concept of 'Normality'

Standards of competence and ability against which you are comparing the individual's functioning and finding common understanding about what is simply to be accepted and 'a normal part of the ageing process' as opposed to being managed or reversed need further definition. The older person themselves may only have stereotypical and therefore usually negative societal perceptions upon which to inform their behaviour and feelings so the task is made considerably more difficult.

Making the difference and finding acceptable methods of proving the 'value added' of support and services continues to be the crux in service development.


Outcomes from Assessment Process
Re - establidhing interaction
Developing Relationships
Improving communication
Identifying Choices
Identifying skills And strengths
Identifying Areas of need
Raising Expectations
Assessment
Defining existing services
Creating new methods of support
Decision Making
Risk Taking
Empowerment

Support Service Outcomes
Empowerment
Indipendence
Social Interaction
Information Access
Mobility
Communication
Reading Mail
News from TV, radio, papers
Reading and filling in forms
Accessing advice and information leaflets
Sell by dates and cooking instructions
Protection from crime
Finding way to shops
Road Safety
Balance / orientation
Answering the door
Communicating with family and friends
Knowing who is around
Participating in group activities

THE UN'S STANDARD RULES ON THE EQUALIZATION OF OPPORTUNITIES FOR PERSONS WITH DISABILITIES IN RELATION TO ELDERLY WITH ACQUIRED DEAFBLINDNESS WITH SPECIAL EMPHASIS ON THE FIRST RULE, "AWARENESS-RAISING".

Kirsten Jansbol (Denmark)

I am pleased and honoured to have the opportunity to speak to you about the United Nations Standard Rules on the Equalisation of Opportunities for Persons with Disabilities in relation to elderly persons with acquired deafblindness.
With the publication of the UN's Standard Rules, the goals for the general disability policy regarding equality and provision of equal opportunity for persons with disabilities have attained concrete form in several key social areas.
And although I know that these rules were not elaborated for the elderly deafblind, (because who in the late 1980s and the beginning of the 1990s thought of elderly people with acquired deafblindness?), the Rules are quite useful for considering what we ought to do or could do to enable society to meet their needs and to give them equal conditions of participation with other elderly people in society.
In my presentation of the Standard Rules, I will begin by talking a little about the background to the rules and the philosophy behind them, and then use more time on the first rule, Awareness-raising. I will conclude with mentioning the other rules as they apply to elderly persons with acquired deafblindness.

The background to The Standard Rules.
Let me talk a little about the background to The UN Standard Rules and the philosophy behind the UN Standard Rules.
As you know persons with disabilities live in all parts of the world and at all level in every society. The number of persons with disabilities in the world is large and growing.
The present disability policy is the result of developments over the past 200 years. Over the years, the policies have been a product of the general living conditions and social and economic policies of different eras. In the disability field, however, there are also many

specific circumstances that have influenced the living conditions of persons with disabilities. Ignorance, neglect, superstition and fear are social factors that throughout the history of disability have isolated persons with disabilities. (And with regard to elderly persons with acquired deafblindness ignorance is one of the keywords.)

As you all know, disability policy has developed from elementary care at institutions to education for children with disabilities and rehabilitation for persons who became disabled during adult life. And through education and rehabilitation, persons with disabilities have become more and more active and a driving force in the further development of disability policy. And as you know, organisations of persons with disabilities, their families and advocates have been established, and advocated improved conditions for persons with disabilities.

Towards the end of the 1960s, organisations of persons with disabilities in several countries began to formulate a new concept of disability. This new concept indicated a close connection between the limitation experienced by individuals with disabilities, the design and structure of their environments and the attitude of the general population. In other words, a person with an impairment becomes disabled in meeting with his or her environments and society.

This new concept has been vital in developing disability policies.

The same time - back in the late 1960s - the problems of disability in developing countries were more and more highlighted. In some of these countries, the percentage of the population with disabilities was estimated to be very high and, for the most part, persons with disabilities were extremely poor.

This situation of many persons with disabilities in the developing countries resulted in the rights of persons with disabilities becoming a subject of much interest and attention in the United Nations over a long period of time. This attention led to the declaration of 1981 as the International Year of Disabled Persons, soon followed by announcing the United Nations Decade of Disabled Persons (1983-1992). The most important result of the International Year of Disabled Persons, was the World Programme of Action concerning Disabled Persons. This programme emphasised the right of persons with disabilities to the same opportunities as other citizens and to an equal share in the improvements in living conditions resulting from economic and social development. This philosophy appears in the Standard Rules, and it is this philosophy which has made the Rules useable in all countries, despite different economic, social and cultural situations.

Some countries wanted the Decade of Disabled Persons to end by a ratification of an international convention on the elimination of all forms of discrimination against persons with disabilities. However, representatives in the United Nations asserted existing human rights documents already guaranteed persons with disabilities the same rights as other persons. Because of this disagreement, they finally agreed instead to concentrate on the elaboration of a new international instrument of a different kind: The Standard Rules on the Equalisation of Opportunities for Persons with Disabilities, which was formed /

elaborated followed by many discussions before The Rules were ratified in the United Nations General Assembly on December 20, 1993.

Although the Rules are not compulsory, they can become international conventions rules when applied by a large number of States with the intention of respecting a rule in international law. The Rules imply a strong moral and political commitment on behalf of States to take action for the equalisation of opportunities for persons with disabilities. The rules set out important principles for responsibility, action and co-operation. They point out areas of importance for quality of life and for the achievement of full participation and equality.

The overall-purpose of the Rules is to ensure that persons with disabilities as members of their society may exercise the same rights and obligations as others.

The set of Standard Rules consist of 22 rules.

The first four rules concerns preconditions for equal participation. They prescribe that there must be created awareness in every country about the needs and rights of persons with disabilities, and that states must ensure access to treatment, rehabilitation and other support services for persons with disabilities, in order for them to participate on equal terms in society.

These preconditions are followed by eight rules concerning target areas for equal participation. Here concrete guidelines are given for ensuring access both to the physical environment and to information and communication, as well as providing education, employment, income maintenance and social security, family life, culture, recreation and sports, and religion.

The last ten rules concern implementation measures, that set up guidelines for governments and other responsible political authorities to use as the basis for initiatives and programs in the field of disability.

Don't worry, I won't talk about them all. As I have said earlier I will concentrate on rule no. 1: Awareness-raising.

In my review of the rule, I will replace the phrase "persons with disabilities" with the phrase "elderly with acquired deafblindness" in order to help us see what opportunities the specific rule contains relating to elderly deafblind people, and to consider what kinds of obligations for the society the individual rule contains in relation to our particular group.

Rule no. 1. Awareness-raising

There are several reasons for my choosing to concentrate on this rule. First, it is the most important of all the rules because increased awareness is a precondition for carrying out any additional concrete measures. Second, one of the most important problems for the elderly with acquired deafblindness is that they do not acknowledge themselves as "elderly with acquired deafblindness", nor do those persons in contact with them. Third, because this rule is less dependent on economic, social and cultural factors in the individual countries than are the other rules. Fourth, because many of the other topics at

this seminar concern the content of the other rules regarding preconditions and target areas. And finally, because awareness-raising is an area with which I have put in a great deal of work as part of the activities of the Information Centre for Acquired Deafblindness. Therefore I can provide practical examples and share with you some of the considerations we have had and describe some of the strategies we have utilised.

Rule no. 1. Awareness- raising:

"States should take action to raise awareness in society about persons with disabilities, their rights, their needs, their potential and their contribution."

Try for a moment to reflect on the possible extent of this rule or sentence:

"States should take action to raise awareness in society about elderly persons with acquired deafblindness, their needs and their rights."

But don't get too happy yet. As I mentioned before, the rules are not binding, but only morally obligating. But all the governments of our countries' have ratified the rule, and are thus morally obliged to take action to raise awareness in society regarding elderly persons with acquired deafblindness, their needs and their rights.

The key words and key questions in the rule are:

"To raise awareness" - How?

"In society" - Who is society?

"About elderly deafblind" - Who are they?

"Their needs and rights" - What exactly are these needs and rights?

The last question regarding "Their needs and their rights" are dealt with in the three other rules for preconditions and for target areas.

Here I will concern myself with the other key words and key questions.

Who are the elderly persons with acquired deafblindness?

I will not attempt a discussion of definitions, but suffice to note the following: the category "elderly deafblind", as is known, consists of a minimum of two groups. One is the very small group of those who have been deafblind since youth or early adulthood and have now become old. Then there is the much larger group of those of interest to us here, elderly persons with age-related deafblindness. Here we often encounter, at least in Denmark, the problem that for those in contact with the deafblind elderly it is difficult to see whether the degeneration of function in the elderly person is a result of a more general ageing process, or whether we can speak of an impairment beyond ageing or not linked with ageing in itself. And here we must argue that if a functional impairment becomes so serious that the earlier lifestyle can no longer be maintained in relation to communication, receiving information and independent mobility due to a combined hearing and vision impairment, then we are speaking of deafblindness.

One of the great barriers in awareness raising is that these elderly persons do not regard themselves as deafblind, but as seeing and hearing persons, who now don't see and hear well anymore.

In this context, the word "deafblind" creates a considerable barrier. Neither the individual elderly deafblind person nor those surrounding them, such as family and professionals, perceive the elderly person as "deafblind". In general, we tend to regard the deafblind as being in the same sensory situation as Helen Keller, that is, totally deaf and totally blind. Yet this condition applies to only a very small proportion of persons with acquired deafblindness.

We therefore face a great and unique barrier in our effort to increase the awareness about age related deafblindness.

Rule Number 1, Awareness raising, has nine sub-points. In the first, the attempt is made to make the concept of Society more concrete. It states:

"States should ensure that responsible authorities distribute up-to-date information on available programmes and services to elderly persons with acquired deafblindness, their families, professionals in the field and the general public. Information to elderly persons with acquired deafblindness should be presented in accessible form."

Let us stop just for a moment to look at the final, somewhat innocent-sounding sentence: "Information to elderly persons with acquired deafblindness should be presented in accessible form." "Accessible form" for the elderly deafblind could consist of audio tape, large print or Braille.

Is there any country in the world which fulfils this very reasonable demand? It should be added, by the way, that this problem area belongs in Rule number 5.

But the key in this sub-point is that "States should ensure that responsible authorities distribute up-to-date information to families, professionals in the field and the general public." The rule thus states as clear as possible who it is who must have information.

As professionals, we need to look more closely at the various target groups for information. Because there are differences between the kind of information needed by family members, the information needed by the public, and the kind of information needed by professionals. The category of "professionals" can perhaps comprise several different professional groups who need different kinds of knowledge depending on the kinds of tasks connected with the elderly deafblind.

The second sub-point refers to a method for increasing awareness and in that it states:

"States should initiate and support information campaigns concerning elderly persons with acquired deafblindness and disability policies, conveying the message that elderly persons with acquired deafblindness are citizens with the same rights and obligations as others, thus justifying measures to remove all obstacles to full participation."

Here we can speak of information campaigns with the ultimate goal "to remove all obstacles to full participation."

When trying to initiate information campaigns about the elderly deafblind, we need to consider several strategic factors.

When we speak of information regarding the elderly deafblind, aside from clarifying exactly who will be the target group for the information, we must also consider how we

can carry on calling attention to such a small group as the elderly deafblind.
Let us look at a concrete example and let me share with you some of our considerations when we wanted to initiate an information campaign directed to home helpers, who in Denmark are the professional group with the most frequent contact with the elderly deafblind living in their own homes and therefore key persons in relation to elderly deafblind persons.

Denmark has a population of five million persons.
Of these, 700,000 are over 67 years old.
Among the 700,000 elderly there are about 2,500 with a combined hearing and vision problem.
Of these, about 900 are deafblind.
How do we create awareness about 900 persons out of 700,000?
How do we conduct an information campaign about 900 out of 700,000?

The answer is probably that you don't!
But among the 700,000 elderly there are approximately 50,000 visually impaired and an additional 350,000 hearing impaired, of which 200,000 use a hearing aid.

The goals of our information for home helpers was, first, to sharpen their awareness about elderly people having a serious degree of combined hearing and vision impairment, and then give them a basic knowledge and some guidelines in their contact with them. In this way, the elderly could obtain more satisfactory benefits from the home helpers, and at the same time the home helpers could provide better service. But good advice on contact with the elderly with a combined hearing and visual impairment is also good advice on contact with elderly with a visual impairment and elderly with a hearing impairment.
Therefore, we thought that if we now joined forces with the Information Centre for Visual Impairment and the Information Centre on Hearing and Deafness, then the target group for the information campaign would cover half of Denmark's elderly, that is, about 50% of all elderly instead of just 0.128% of all elderly. We thought that this would mean that the leadership of the municipal home care services would become so interested in this information that they would feel more willing to give the home helpers time to acquaint themselves with the information, which is necessary for the home helpers in order to acquire the basic knowledge about dealing with the elderly with acquired deafblindness – which is in turn a precondition for changing behaviour toward the elderly deafblind.
These strategic considerations led to the booklet, "When Vision and Hearing Fail", and 55,000 copies, which is a high number for Denmark, being produced. The booklet was sent out to all directors of social services in Denmark's municipalities by the National Association of Municipalities, which unites all the municipalities in Denmark, with an appeal that it be distributed to all personnel working in the municipal home care services, numbering about 50,000.

That the Association of Municipalities distributed the booklet was another of the special considerations we had. When sending a letter to the municipality's director for social services with the appeal to ask staff members to read "When Vision and Hearing Fail" there is a great difference in the authority behind it depending on whether the appeal comes from the Information Centre for Acquired Deafblindness or from the Association of Municipalities.

"When Vision and Hearing Fail" has clearly created awareness, including awareness about the specific group of elderly persons with acquired deafblindness. But much more is needed before increased awareness —in the form of information — can produce changes in behaviour, which is certainly the goal with the increased awareness.

There must also be some kind of education or training, in e.g. the job situation.

We have therefor put together a packet of materials which we sent out to all the municipal home care giving units during this summer. The packet has three objectives:

1) to enable the municipality to be aware of and be able to identify those elderly who have acquired deafblindness;
2) to create awareness among municipal staff about the situation of elderly with acquired deafblindness; and
3) to suggest possibilities for action.

The awareness-raising material demands a time investment by the municipality of just one hour for the staff members. And this hour is used as follows:

The municipal home care office desires to upgrade the qualifications of personnel who deal with elderly persons with hearing and/or vision impairment. A meeting is arranged at the end of the work day, where the deafblind consultant briefly explains the purpose of the initiative, shows the video "Something Can Be Done", which we, at the Information Centre for Acquired Deafblindness have also produced, asks the participating staff members to read three case studies concerning elderly people with acquired deafblindness, and finally, asks them to consider their clients and decide whether they have hearing problems, vision problems or both. If the home helpers have any clients with these problems, they should fill in this form (shown in the overhead) which is to be used in order to give those elderly with hearing or vision problems a relevant assistance.

The entire process, as stated, takes about an hour, and personnel will have obtained heightened awareness of elderly people with hearing and/or vision problems by taking an active position on these problems.

Here we find yet another strategic consideration. If we succeed in creating a heightened awareness about the elderly deafblind and their situation, we must on behalf of the systems which offer services to the elderly with acquired deafblindness, think in terms of better resource utilisation. For example, we could have made a program for home helpers which took three hours, and thereby given them even more knowledge. But the chances are very small that the municipalities would have set aside three hours for all their home

helpers in order to learn about this small group of elderly with acquired deafblindness.
We have a Danish proverb which says, "The best must not become the enemy of the good." For example, if we had only pursued the goal of a three-hour course for home helpers, which is unachievable, we would have failed in obtaining even the one hour information meeting. Then we would have allowed the best solution to become the enemy of good solution. We have made similar considerations in connection with many of our activities, including that which I will mention now.
As a pilot project in two counties, we have brought the hearing advisory unit, the vision advisory unit and the regional deafblind consultant together to offer a course on the elderly with hearing and/or vision problems directed to key personnel in the municipalities' home care services. The course is of six hours duration and is both awareness-raising and action-oriented. Behind this project – beside thinking in resource-conscious terms on behalf of the system – lay other strategic considerations in connection with awareness-raising for the small group of elderly people with acquired deafblindness. Denmark's five deafblind consultants and the two staff members at the Information Centre for Acquired Deafblindness cannot handle the work effort needed to create effective awareness about elderly persons with acquired deafblindness in all of Denmark's 275 municipalities.
More actors are needed.
In Denmark, as in most countries represented here, there is a visual impairment unit and a hard of hearing unit of some kind at the regional/county level. These advisory systems must be made more active in awareness raising work about elderly deafblind people, for example, in the form of the six-hour training course mentioned above. Only by getting more actors into the field can the awareness raising work obtain the necessary effect.
A very great additional advantage of this project is that the two advisory systems for people who are, respectively, hearing and vision impaired become aware that they have clients who have a double impairment, and whom they must take into consideration if they are to provide these persons competent advice in connection with e.g. technical aids. Coordination of the regional hearing and vision efforts is necessary in order for the elderly to obtain adequate treatment. But this problem belongs to Rule number 3, which concerns rehabilitation. Frank Jorritsma, Yvonne Jonsson and Jan Prickarts have told us about how it is done in Holland.
Has this, relatively comprehensive, awareness-raising effort in Denmark had any effect? This is, of course, very difficult to measure, for much so-called "soft data" enters into any such measurement or assessment. But a more tangible goal could be the number of elderly deafblind who are referred to the countrywide deafblind consultant system. These referrals typically come from the municipal system.
When the Information Centre for Acquired Deafblindness began its awareness raising activities about three years ago, the deafblindness consultants had knowledge of 176 persons with acquired deafblindness (both elderly and younger). Today they are in contact with 286 persons, and the number of referrals of deafblind persons to the consultants is

constantly increasing and primarily elderly. It is an increase of nearly 60% over a three year period.

One can therefore conclude that awareness-raising work results in more elderly with acquired deafblindness becoming identified and thereby obtain the possibility to utilise the national facilities available for people with a serious degree of combined hearing and vision impairment.

As conclusion about Rule number 1, Awareness-raising, I will cite the sub-point number 7, which states:

"States should initiate and promote programmes aimed at raising the level of awareness of elderly people with acquired deafblindness concerning their rights and potential. Increased self-reliance and empowerment will assist elderly deafblind people to take advantage of the opportunities available to them."

I will now proceed to the final part of my presentation and refer to the rules which are relevant to elderly persons with acquired deafblindness, and comment upon them.

Rule 2. Medical care.

"States should ensure the provision of effective medical care to the elderly with acquired deafblindness."

All of us can agree on this. But the reality in Denmark, for example, is that there can be up to a year's waiting time for a cataract operation, and up to 16 months' waiting time to obtain a hearing aid. These are two critical areas for the elderly person with acquired deafblindness. This example clearly shows that willingness to fulfil the needs of persons with disabilities depends on our priorities, nationally and internationally.

While preparing this presentation, the Human Development Report appeared under the auspices of the UNDP, the development program of the United Nations. The report does not make pleasant reading. Let me give you just a few examples to illustrate our priorities. It will cost nearly 9 billion dollars to ensure that all people in the developing countries have water and adequate hygienic conditions, as a result of which thousands of people could avoid becoming blind; and it will cost an additional 12 billion dollars to ensure basic health conditions and food for all people in the developing countries, which again would ensure that thousands of people could avoid becoming blind or suffering from other disabilities.

In comparison, in 1997 the Europeans and Americans used 11.5 billion dollars on perfume and 16 billion dollars on food for their pets, and the Europeans consumed no less than 4 billion dollars worth of ice cream. How many cataract operations could we get for four billion dollars? But ice cream tastes good and perfume smells nice!

Back to rule no. 2, which also mentions that staff should have relevant training. In sub-point number 4 it states:

"States should ensure that all medical and paramedical personnel are adequately trained and equipped to give medical care to elderly people with acquired deafblindness and that

they have access to relevant treatment methods and technology"
At the Information Centre for Acquired Deafblindness we have recently published a booklet entitled "Good Communication with Patients Who Have Impaired Vision and/or Hearing". The booklet could be seen as a part of the training which medical personal need in order to be able to better communicate with elderly persons with acquired deafblindness. We have brought the booklet, and we will send you the English translation as soon as it is finished.

Rule 3. Rehabilitation

Many of the presentations at this seminar concern rehabilitation, so it can be certainly very interesting to examine what the UN's Standard Rules state about this:
"States should ensure the provision of rehabilitation services to elderly with acquired deafblindness in order for them to reach and sustain their optimum level of independence and functioning."
With the first two sub-points:
"States should develop national rehabilitation programmes for all groups of persons with disabilities. Such programmes should be based on the actual individual needs of the elderly with acquired deafblindness and on the principles of full participation and equality."
"Such programmes should include a wide range of activities, such as basic skill training to improve or compensate for an affected function, counselling of elderly with acquired deafblindness and their families, developing self-reliance, and occasional services such as assessment and guidance."
Many here at the seminar have talked about how this can be done. Frank, Yvonne and Jan have shown how the necessary coordination between hearing and vision rehabilitation can take place, and they have told us about their holistic approach to rehabilitation. Liz Duncan and Martha Bagley have talked about the very important aspect of rehabilitation for the elderly with acquired deafblindness, communication, and finally I will mentioned Sarah Goodwin and Tony Kirk's presentation of the project "Assessing and meeting the needs of older sensory impaired people" with emphasis on self-reliance and empowerment, maybe the most important part of rehabilitation.
The final sub-point in the rehabilitation rule which I will cite is
"All rehabilitation services should be available in the local community where the elderly with acquired deafblindness live."

Rule 4. Support services

"States should ensure the development and supply of support services, including assistive devices for elderly with acquired deafblindness, to assist them to increase their level of independence in their daily life and to exercise their rights."
With sub-points 1 and 6:

"States should ensure the provision of assistive devices and equipment, personal assistance and interpreter services, according to the needs of elderly with acquired deafblindness, as important measures to achieve the equalisation of opportunities."
"States should support the development and provision of personal assistance programmes and interpretation services, especially for persons with severe and/or multiple disabilities. Such programmes would increase the level of participation of elderly with acquired deafblindness in everyday life at home(, at work, in school) and during leisure-time activities."
Helle Brøgger has in her workshop shown how personal assistance services can be provided and how they can operate.
And now to the last that I will mention:

Rule 5. Accessibility
"States should recognise the overall importance of accessibility in the process of the equalisation of opportunities in all spheres of society. For persons with disabilities of any kind, States should (a) introduce programmes of action to make the physical environment accessible; and (b) undertake measures to provide access to information and communication."
Here I will limit myself to quoting from:
(b) Access to information and communication
With the sub-point 6:
"States should develop strategies to make information services and documentation accessible to different groups of persons with disabilities. Braille, tape services, large print and other appropriate technologies should be used to provide access to written information and documentation for persons with visual impairments. Similarly, appropriate technologies should be used to provide access to spoken information for persons with auditory impairments or comprehension difficulties."
And we can add, that when this becomes a reality, access to information for the elderly persons with acquired deafblindness will have been established.
But how do we ensure that elderly people with acquired deafblindness, as members of their societies can exercise the same rights and obligations as other elderly people?
I don't have the answer.
But I believe that if we disseminate the knowledge of the UN Standard Rules on the Equalisation of Opportunities for Persons with Disabilities and utilise them in a constructive fashion, we can come a little bit further toward our goal.
This seminar is the second time in two years that the Standard Rules have formed the basis for discussions of the situation and services for persons with acquired deafblindness. The first time was in Poitiers, France, in 1996. I am sure that events like these support the implementation of the Standard Rules in the practice and policy making of professionals in Europe.

But in the end, the real value of the Rules depends most of all on whether we as professionals and organisations of persons with disabilities use them or not.
Therefore, go home and read them, and use them to the benefit for the elderly with acquired deafblindness
Thank you for listening!

THINK DUAL SENSORY: POLICY AND PRACTICE INITIATIVE

Jeff Bashton (United Kingdom)

QUOTES FROM DEAFBLIND PEOPLE

"I'm deafblind and so was my husband. I've not been out since he died 8 years ago. I hate being alone. I've learned to close my mind so I don't have to think about it."

"When I go shopping I could do with a guide to bring the scene to life, so to speak, tell me the prices and the new offers. On one trip I did have such help and it made all the difference and I enjoyed it."

"It's the little things that I fancy, like knowing how to use the microwave, and how to tell when someone's at the door."

"They should make sure the deafblind manual is taught to people in local authorities and in the services it provides, its police, ambulance, the social services, in the hospitals, and any place that may be of help."

THINK DUAL SENSORY:
THE APPROACH

- SECRETARIAT
- STEERING GROUP
- SEMINARS
- VISITS
- LAUNCH OF DRAFT
- WORKSHOPS

FINAL VERSION

Purpose

The objective of this presentation is to acquaint you with the outcome of a series of linked activities that resulted in a publication "Think Dual Sensory" designed to raise the profile of older deafblind people.

This presentation will fall roughly under the following headings:

- Philosophy
- Approach
- Objectives
- Outcomes/conclusion

Yes, you guessed it, the buzz words. But I think these words will provide us with a useful

way of erecting boundaries around different aspects of this three year initiative - 1994-1997.

Philosophy

The intellectual approach taken was unashamedly eclectic. We at the centre, a policy civil servant colleague and myself, took responsibility for steering the process. We didn't claim expertise in dual sensory loss! We wanted the initiative to integrate aspects of deafblindness into the health and social context arena, but not have it submerged by it. We took the principles from an initiative known as "Living Options in Practice" as the philosophical base. These six principles are:

Choice about where to live and how to maintain independence, without over protection or the risk of unnecessary hazards, including help in learning how to make choices.

Consultation with people with disabilities, and their carers and families, on services as they are being planned.

Information that is clearly presented and readily available to all users, including those with severe disabilities.

Participation in the life of local and national communities, in respect of both responsibilities and benefits.

Recognition that long term disability is not synonymous with illness, and that the medical model of care is inappropriate in the majority of cases.

Autonomy, meaning a person's freedom to make decisions about the way of life that is best suited to their individual circumstances.

The Approach

The initiative was secured by obtaining Ministerial approval and consequent funding for a project that focused on older deafblind people. The secretariat for the project consisted of an administrative and professional civil servants and I, as one of these, used my knowledge of the deafblind sector to gain the support of informed others to become steering group members.

Terms of reference for the group were devised but they are not labelled as such in the final document. Instead we pose the question "What do we mean by dual sensory loss?". There is no definition of deafblindness or dual sensory loss in the UK, simply a description of some of its effects; but the document refers to people "whose combined sight and hearing losses cause difficulties with communication, access to information and mobility". Any degree of loss of sight or hearing can result in confusion, loneliness and isolation. Lack of information removes the ability to make informed decisions and also threatens independence. The terms of reference concentrated on the distinctness of deafblindness. Whilst recognising the uniqueness of individuals it distinguished five groups of older deafblind people, ranging from the majority "those whose dual sensory loss has developed in old age" at one end of the continuum to "older people who have had dual sensory loss throughout all or most of their life" at the other.

The work concentrated very much on locating where there was existing good practice, and sharing it with others who wanted to establish similar services. This approach formed the basis of two seminars for the sharing of information. Additionally steering group members made visits to local authorities. Questions or discussion points were devised to give focus to visits and assist in comparing similar topics in different settings. All visits included meeting with older deafblind service users. The interview prompts were later used in the document as key questions at the end of chapters as a way to actively engage the reader/service planner or provider.

Seminars

It was intended that the information gathered at the seminars and the major issues raised be used to inform the content of the good practice document. In particular, examples of good practice presented at the seminars, were documented for inclusion in the document. Major issues of concern presented by participants were recorded and if feasible addressed in the guidelines prepared for the good practice document.

In short the seminars were a cost-effective and time-economic way of:

a. Bringing together current practitioners in this field to map existing practice.
b. Creating awareness and anticipation in relation to the forthcoming good practice document
c. Identifying possible obstacles to the good practice document being implemented.
d. Raising the profile of the elderly deafblind within local authorities.

The seminars took place in early 1995 approximately six weeks apart.

SEMINAR 1

The first seminar was targeted at twenty to thirty key senior managers within local authorities already providing some strategic service to elderly people with dual sensory impairment. It involved invited elderly deafblind people to give their views as recipients of the services provided. The day included an introduction to the work of the Department of Health steering group on good practice, case studies and participative plenaries on the issues facing managers and practitioners in assessing, locating and providing for such an 'invisible' and minority client group. The seminar was written up in the form of a report which:

i. Described existing practice
ii. Recorded the major issues to be addressed

SEMINAR 2

The second seminar followed on from the first, using material gathered from that day. This seminar targeted key senior staff from authorities which had not yet developed practice in this area. The aim was to raise awareness, present some of the examples of practice from Seminar 1, and again elicit from participants the difficulties they perceived in assessing

and providing for the elderly dual-sensory impaired.
In addition, this seminar was aimed at identifying a small number of authorities (three to four) which would be prepared to follow through the guidelines of the Department of Health good practice document in the development of their services (and therefore contribute to the evaluation of the piece of work).
Seminar 2 included an introduction to the good practice document, case studies, a particular focus on the nature of deafblindness and the needs of deafblind people and plenaries/discussion groups.

Visits
Having devised questions on various topics e.g. assessment, training, budgets etc members of the steering group visited authorities in pairs. In effect this was a fact finding exercise to inform steering group members and to be considered for incorporation into the good practice guidelines document.
In summary phase 1 of the project, from mid 1994 to the end of 1995, consisted of steering group meetings, agreeing terms of reference and setting the future work of the group, organising, attending and documenting seminars. A nonspecialist writer was commissioned to produce the draft version of the good practice guidelines. These were publicised at a specialist seminar whose purpose was to launch the findings of a project on training volunteers to work with deafblind people.

Phase 2
Volunteers to pilot the Guidelines were recruited from the two seminars which we used in Phase 1, the seminar that publicised the draft and a larger seminar hosted by the Association of Directors of Social Services on Sensory Disability. A letter was written to those "volunteer" authorities and we told them that during the year between the first (draft) and second (final) editions of these Guidelines we hoped to improve their usefulness by identifying and remedying omissions, amending the text to prune out unnecessary sections and amplify others. The letter went on to say that if local authorities were planning to develop services for older people with dual sensory loss they could undertake to develop some aspect of a topic covered in the document and report back by letter or in person at workshops. They were free to either cover topics in the Guidelines or choose others of most help to them. Topics included, identification, contracting out of services, use of volunteers, training, consultation of users, and the inter-face between health and social care.
In return for their participation the Department of Health offered: encouragement, support and advice of the Social Service Inspectorate and the group of fellow pilots through workshops plus the opportunity to publicise their good practice and influence and amend an important publication!

The Workshops
There were four workshops whereby 2/3 colleagues from the Department of Health

worked with approximately 12 authorities with two people from each.
Workshop participants chose which aspect of service to work on and usually did this with one other authority. Brief descriptions of their work form an appendix to the document.
I view this appendix on "The Pilot Work of Local Authorities and Health Authorities" as one of the most important parts of the document. Not only does it provide contact names, addresses and telephone numbers of those undertaking specific work with deafblind people: but it also lists what documents can be obtained from them. Thus, those wishing to develop services for older deafblind people can obtain a job description and person specification for a communicator guide, reports to committees arguing for resources, user surveys etc.
The contents and appendices of Think Dual Sensory: Good Practice Guidelines for Older People with Dual Sensory Loss are as follows:

CONTENTS

1. Introduction - purpose of the document
2. Getting started: the need for better provision
3. Setting up new services
4. Developing existing sensory services
5. Making general services available to deafblind users
6. Securing the service

APPENDICES

1. Three case histories
2. The pilot work of local authorities and health authorities
3. Publications, resources and contacts
4. Job description for a deafblind communicator-guide
5. Screening sheet for an individual with both poor vision and hearing difficulties

Conclusion

I believe this three year multi-activities project with a draft and a final version of Guidelines has done much to clarify the thinking around older people and dual sensory loss in the UK and raised the profile. The involvement of many stakeholders, including users, the engagement of a freelance writer who could approach the project in a somewhat more detached manner, and the involvement of those on the ground actually running the services have all contributed to the richness of the Guidelines.

PLENARY SESSION ON UK POLICY

Peter Kaye (United Kingdom)

This presentation paper gives an example of how one UK Authority - Bradford - has attempted to develop policies around the needs of older people with acquired deafblindness.

First a little bit of background about Bradford's initiatives to provide services to deafblind people in general.

By the end of 1991 it was clear to officers in Bradford that the city needed to better identify the numbers and needs of deafblind people locally, that a designated person was needed to assess the needs of identified deafblind people and that agreed policies and designated services for deafblind people were required.

This led to the appointment in July 1992 of a specialist worker. Her initial work led to a number of issues being highlighted:

- the intensive amount of time that some deafblind people require to fully assess their needs.
- the importance, if possible, of establishing communication methods at an early stage.
- the numbers of deafblind people who are elderly.
- the particular difficulties that carers of deafblind people face.
- the fact that many pieces of equipment need to be re-adapted for use by deafblind people.
- the need for sighted guides.

As a result of this initial work, a report was prepared for the Councils' elected members in January 1994, when it was agreed to:

- recruit and train sighted guides.
- identify a specific budget for equipment and adaptations.
- consider what further steps should be taken to improve the quality of life of older deafblind people.

This report provided an Agenda for Action and validated the work undertaken by the specialist worker. Also in 1994 for the first time Bradford separately identified the needs of deafblind people in its Community Care Plan developed jointly between the Health and Local Authorities.

Because of Bradford's initiatives key officers were invited to assist in the development of the Department of Health (Social Services Inspectorate) Guidelines "Think Dual Sensory". The Council were subsequently one of twelve authorities who agreed to pilot

the guidelines. In July 1995 Bradford Council approved a strategy for Older people who had acquired dual sensory loss. That strategy recognised six key elements:

1) Communication needs: ways of introducing communication mechanisms for older people and their carers/families at the earliest opportunity.
2) Information: about what help is available and how people can access that help, backed up by a campaign involving the key staff who may come across older people with acquired dual sensory loss in their work.
3) Equipment provision: Not only the creation of a separate ring fenced budget but the development of a Resource room for deafblind people to be able to try out pieces of equipment for themselves.
4) Training staff: in which three key areas were identified.
    a) Front line staff, e.g., Home Care, day care and residential care staff - to increase awareness of deafblindness.
    b) Specialist staff, working with blind people or working with deaf people so that they may be better able to recognise and support the needs of people with dual sensory loss.
    c) Further specialist training for the specialist worker herself so that she could provide more effective services.
5) Support for Carers - a group was established targeted mainly at carers, but open to deafblind people and workers locally (The Consensus Group). This group decided that they would learn the deafblind manual and guiding skills and has now become a social support group.
6) Social Support - specific assistance to staff providing support to older people in day resources to be able to better include those with a dual sensory loss.

As part of piloting the Think Dual Sensory Guidelines and in response to the Strategy, Bradford undertook a survey of all the residential and nursing homes in the District. It did this by producing a survey questionnaire and, in conjunction with Sense, an information pack. The questionnaire and information pack were forwarded to every establishment caring for older people in the district. Bradford then held a training event for staff from these establishments to raise awareness of the needs of older people with acquired dual sensory loss and also to advise them how to complete the questionnaire.

The outcomes of this survey were published in 1996. The survey identified 90 older people, not previously known to the specialist worker, who had some degree of combined visual and hearing loss. Follow up contacts have been made to ensure that the needs of each person are being appropriately addressed.

Bradford established its own Guide Support Scheme in 1997 in order to provide support to people, to relieve isolation, prevent withdrawal and increase opportunities for inclusion and independence and thereby improve the quality of the lives of people with dual sensory loss.

A report on the first year of the Scheme was presented to elected members in February 1998. At that time the service had been used by 14 people (70% of whom were over 65) and had proved invaluable to those who had used it. Elected members have agreed to receive a further report in February 1999 when the outcome from the Schemes' pilot 2 years will be evaluated for its inclusion in main stream service.

This service currently offers

- Befriending - regular home visits
- Reading and dealing with correspondence
- Developing communication skills
- Going on shopping trips, walks, outings
- Escorting to health appointments
- Promoting self-advocacy, self-confidence in individuals

There is a reference group overseeing the project that involves three deafblind people. They are keen to see the project develop and do so in ways that meet the needs of all deafblind people locally.

A further initiative that followed on from the strategy was the provision of a training course for Home Care staff around increasing awareness of older people with acquired dual sensory loss. So far three courses have been run (with Liz Duncan from Sense as the trainer) and more are planned. Evidence from those trained would suggest that 66% considered that they had or were working with someone with acquired dual sensory loss and that 50% only realised this as a direct result of attending the training course.

Services in Bradford have only occurred following the development of policies and strategies.

Crucial in this process has been a succession of reports (four in total this far) to elected members to seek and obtain political approval. The endorsement of the strategy for older people with acquired Dual Sensory Loss in July 1995 underpinned future service developments.

Elected members are proud of Bradford's reputation as a leading Authority within the UK in relation to this area of work. This has enabled officers to push for further service developments in order to retain this reputation.

Currently in Bradford a joint Health/Social Services review of services to people with Sensory loss is taking place. Within that review another opportunity exists to further include the involvement of key Health professionals both in the assessment of need and in the co-ordination of service provision. Consultation is taking place with services users in relation to how they would like to see services organised in future. Another report will go to elected members on the outcomes of this review. The Authority are also currently in negotiation with Bradford University and an emerging Primary Care Group of General Practitioners (GP's) to introduce a systematic screening for both hearing loss and vision loss in people aged 75. Bradford has obtained Health Action Zone funding and it is hoped

that resources will be available to develop this project over a number of years. It is hoped that amongst other outcomes the Project might result in:

1. An agreed screening protocol throughout the District - this may then be available throughout the UK.
2. Agreement to introduce screening at an earlier age.
3. Earlier detection of dual sensory loss and therefore more effective strategies to maximise any residual sight/hearing.
4. Reductions in loss of confidence and in dependence in many older people.
5. Reductions in falls in older people - one startling UK statistic is that 20% of all falls in older people that result in fractured neck of femur arise from people having poor vision - often previously undetected or not compensated for.

A final thought on policy development is the role Bradford have played in encouraging and developing two UK wide initiatives. Firstly, the development of a meting of Local Authority professional staff working with deafblind people - this group meets every six months in different parts of the UK to maximise the opportunities of people from different areas to attend.

Secondly, the development of a UK wide newsletter "Sensored" which now has a circulation of over 400 people and again is distributed every six months and comes out in-between the meetings of specialist staff. The next meeting will take place later this month in Bradford when the specialist topic for discussion will be the more specific needs of older people with acquired dual sensory loss. In this way the group hopes to help influence policy in different UK authorities.

POLICY ISSUES HIGHLIGHTED BY SPECIALIST WORKER IN REPORT TO ELECTED MEMBERS IN JANUARY 1994

- Intensive amount of time that some deafblind people require to fully assess their needs
- the importance, if possible, of establishing communication methods at an early stage
- the numbers of deafblind people who are elderly
- the particular difficulties that carers of deafblind people face
- the fact that many pieces of equipment need to be re-adapted for use by deafblind people
- the need for sighted guides

STRATEGY FOR OLDER PEOPLE WITH DSL

- COMMUNICATION NEEDS
  - early introduction of deafblind manual or other means of communication
  - sufficient people to each means of communication
- INFORMATION NEEDS
  - about assessments
  - about services
  - different formats
  - for carers
- EQUIPMENT PROVISION
  - ring fenced budget
  - equipment room
- TRAINING OF STAFF
  - frontline staff
  - specialist single sensory loss staff
  - for the specialist worker
- SUPPORT FOR CARERS
  - consensus group
  - guide support scheme
  - volunteer visitors
- SOCIAL SUPPORT
  - consensus group
  - service reference groups

GUIDE SUPPORT SCHEME

- befriending - regular home visits
- reading and dealing with correspondence
- developing communication skills
- going on shopping trips, walks, outings
- escorting to health appointments
- promoting self-advocacy
- promoting self-confidence

PROPOSED GP SCREENING PROCESS FOR PEOPLE AT AGED 75
(HOPED FOR OUTCOMES)

- Agreed screening protocol throughout Bradford
- Use of the agreed protocol elsewhere within UK
- Introduce screening at an earlier age
- earlier detection of dual sensory loss

- reductions in loss of confidence in older people
- reductions in loss of independence
- reductions in falls in older people

COPIES OF INFORMATION AVAILABLE FROM BRADFORD

- REPORT TO COUNCIL ELECTED MEMBERS
  25 JANUARY 1994
- REPORT TO COUNCIL ELECTED MEMBERS
  6 JULY 1995 (includes Strategy for Older deafblind people)
- REPORT TO COUNCIL ELECTED MEMBERS
  21 NOVEMBER 1996
- REPORT TO COUNCIL ELECTED MEMBERS

4 FEBRUARY 1998 (Guide Support Scheme for Deafblind People)

- Survey of Elderly People with a Dual Sensory Loss living in Nursing or Residential Homes in Bradford 1996
- Bradford Guide Support Scheme Policy Document

OBSTACLES TO OLDER DEAFBLIND PEOPLE GETTING A PROPER SOCIAL SERVICE

Graham Willets and Brian Peaker (United Kingdom)

- In this workshop we will be focusing on older deafblind people.
- Voluntary organisations such as Sense, Deafblind UK and increasingly RNIB are focusing on services for older deafblind people.
- BUT the statutory (or State) sector has a long way to go.
- We want to focus on why that is and to look for solutions with our colleagues in the workshop.
- Local State specialist services in the UK are nearly always provided for deafblind people either by a Social Worker with Deaf People, or by a Rehabilitation Worker with Blind and Partially Sighted People. It is likely that the Social Worker with Deaf People does not know too much about blindness and it is just as likely that the Rehabilitation Worker with Blind and Partially Sighted People does not know about deafness.
- BUT, to complicate matters, we are talking particularly about older deafblind people so there is a further problem. Social Services departments in the UK tend to have special sections for older people which organise and manage services for older people through Residential Care, Day Care and Domiciliary Care. The specialist social workers with deaf or blind people might not have a good knowledge of what those older people's services are and how they can be provided. It is important for us to stress – there is not always a good, clear connection between those services that are provided for older people and those services that are provided for people with a sensory or dual sensory disability.

So the problem is that there is a committed and well-developed voluntary sector. We, at RNIB, in our work with Social Services in the statutory sector find that there is a will to improve services for deafblind people BUT there is limited knowledge about deafblindness amongst specialist workers and others.

Just as importantly, statutory organisations are structured in such a way as to make it difficult for staff in different departments to have understanding of, and access to, each other's services. They are usually very separate.

It seems as important to us for people working in the statutory and voluntary sectors to have a good understanding not just about deafblindness but a similarly good

understanding about all the services for older people that could and should be made more accessible to older deafblind people.

"Obstacles to older deafblind people getting a proper social service"

This workshop resulted in discussion between U.K. and Dutch delegates only. It is unfortunate other countries were not represented, nevertheless there was a wide-ranging dialogue between all present, featuring the comparison of service structures in the two countries.

The workshop leaders presented some information about how Social Services Departments (local government bodies) are organised in the U.K. There is often very poor communication between professionals who work in general with older people and those specialists who work with people with either sensory impairment. The structures reflect and reinforce these obstacles. The situation is not dissimilar in the Netherlands, but has improved recently, so that older people referred for social services now have a better chance of having losses of sight and hearing recognised.

There was an associated debate about how to tackle this problem. A suggestion was made that in some cases it might not be easy to persuade these statutory organisations to change their structures. Instead, perhaps in those circumstances it would be better for the voluntary organisations to seek to provide the services under contract. We did not have enough time to properly weigh up the advantages and disadvantages of such an option.

LIFE QUALITY SURVEY IN FINLAND INTERVENTION PROGRAMME FOR ELDERLY DUAL SENSORY IMPAIRED PERSONS

Else Marie Svingen (Norway) and Marja-Leena Saarinen (Finland)

Basic principles in geriatric policy and modern concept of the elderly

Basic principles in geriatric policy are: normalisation, respect for elderly persons, safety, social interaction, autonomy, individuality, freedom of choice, pluralism, equality and justice. These are the principles that have to be followed when social services for the aged are being planned and produced. In addition, these are the principles that should be internalised by all professionals providing services. These very principles are lived out in practice in the Nordic deafblind work.

A modern concept of the elderly is gradually becoming part of people's attitudes. Ageing is a psychosocial process based on individuality, personal philosophy, needs, resources, history and functional environment. By discussing the resources of elderly persons we develop an approach to their quality of life, which means a full life including participation in society.

Participation and learning

The aims of geriatric policy – participation and learning - emphasise the resources of elderly dual sensory impaired persons. They have wide effects in terms of:

1. creating a society where full participation is possible,
2. ensuring the possibility of fulfilling oneself and lifelong learning.

Learning process supports the elderly dual sensory impaired persons' coping in everyday life. The life situation is constantly changing because of ageing and adjustment to the dual sensory impairment. The elderly are trying to adapt themselves by developing new strategies in order to maintain their functional capacity. Functional difficulties may cause problems with self-esteem.

Aspects of quality of life related to elderly dual sensory impaired persons

Often the message from elderly persons with dual sensory impairment to other people may be: "I'm alright – I don't need anything special. It is old age, you know". They do not feel impaired or deafblind. Their identity is the same as it has always been throughout their lives. Modern gerontological research results follow that theme: Young or old, people feel they are the same; ageing does not change the personality but changes biological and physical features.

A life quality survey of the sense of coherence of dual sensory impaired persons (N=30) was carried out in Finland. The results were compared with a group of seeing and hearing elderly persons (N=300) . The comparison showed that the sense of coherence is almost similar in both groups.

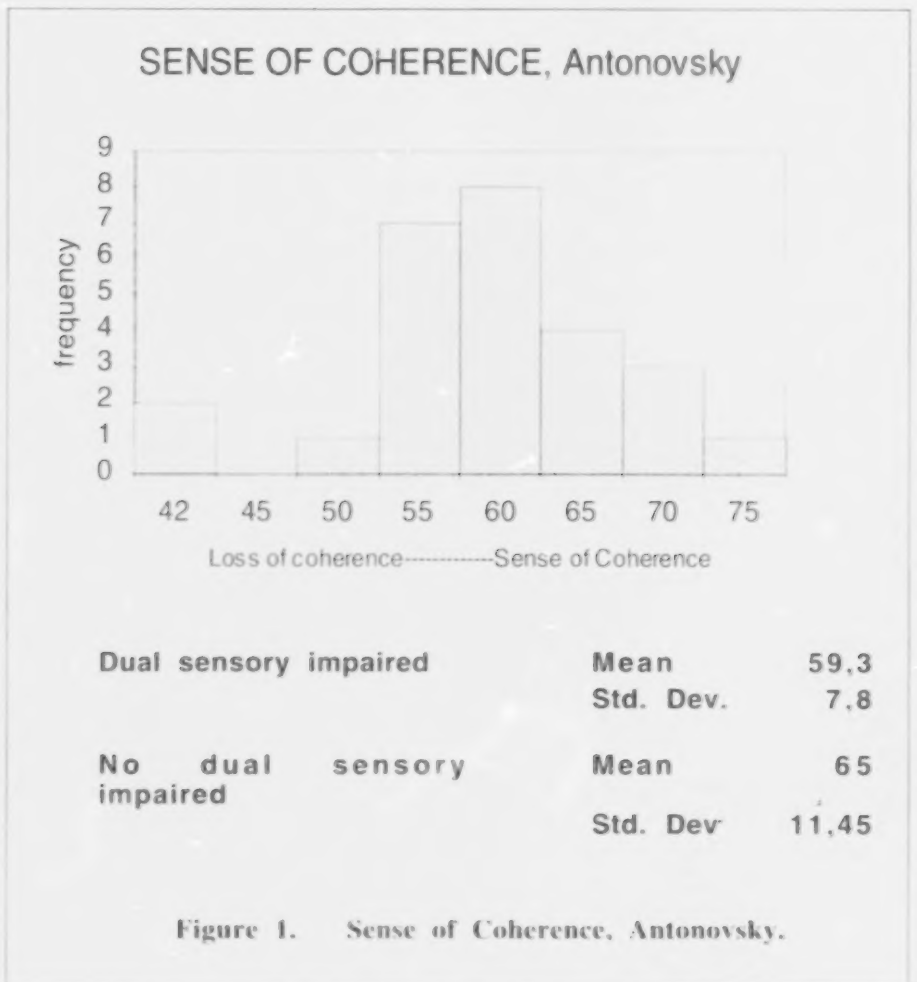


Figure 1. Sense of Coherence, Antonovsky.

This result show that quality of life is formed by a subjective conception and feeling of oneself. Another aspect is that it is the ageing itself and not so much the dual sensory impairment that brings new factors into quality of life. Prerequisites for a good quality of life are the possibility to feel significant and harmonious as well as to influence one's

environment and to control it. Good life feels purposeful and valuable.

Description of life situation of elderly dual sensory impaired persons

Although elderly dual sensory impaired persons do not see any difference between themselves and hearing and seeing elderly persons, they do have very serious problems. According to the survey the group of elderly dual sensory impaired persons can be described as follows:

- they communicate with speech and not with sign language
- 50% do not hear speech well enough to have a dialogue
- 62% have difficulties in recognising another person using sight only.
- 83% have difficulties with ADL.
- 66% have difficulties with mobility outdoors.
- 75% have difficulties in participating in various activities: church, meetings, hobbies.

Elderly dual sensory impaired persons have special difficulties in communication, access to information and mobility. Functional obstacles caused by these difficulties are present in the life situation of elderly persons and they need a lot of support and assistance. Elderly dual sensory impaired persons use considerably more social services for the aged than their hearing and seeing peers.

Functional definition of deafblindness and elderly dual sensory impaired persons

The Nordic definition of deafblindness emphasises functionality. Combined visual and auditory impairments mean a separate disability of dual sensory impairment which related to the functional obstacles of ageing added to functional difficulties of the senses.

Ageing makes mobility more difficult. Elderly persons have rheumatic diseases, heart diseases and problems with balance. Tactile sense in fingers, sense of smell and taste have weakened. Functional disorders in remembering and forgetting are everyday life for an elderly person. Even a moderate dual sensory impairment combined with the elderly person's functional obstacles demands from the environment special attention and internalising the meaning of preventive work.

Deafblindness combined with ageing demands interdisciplinary co-operation. It is necessary to combine geriatric and gerontologic knowledge with expertise of deafblindness.

QUALITY OF LIFE RESEARCH DATA FROM A DEMOGRAPHIC SURVEY OF DEAFBLINDNESS IN THE ELDERLY NORWEGIAN POPULATION

Else Marie Svingen (Norwegian Central team for Deaf-Blind)

Introduction

This presentation is based on data from a Norwegian nation-wide demographic survey of serious combined visual and auditory impairments in the elderly. The survey was carried out in 1997 and included screening. Its goal was to identify deafblind people over 67 years of age who were previously unknown to us, and it included a follow-up phase during which about 80 people were visited in their homes.

The elderly were asked questions about their experiences concerning their vision and hearing impairments, how and to what degree the impairments affected their daily life, socially, emotionally and practically. This information and the assessments that were made tell us something about needs of rehabilitation, measures in main areas and different levels to obtain a better quality of life.

Definition of the term: Quality of life

The subject of this workshop is "Quality of life research". The concept of "quality of life" is often used, and, in many contexts, without us always being so careful to define what we mean by this concept.

To put it simply, quality of life is to do with our feeling of whether we live a good or bad life. The expressions "having a good life" and "quality of life" are often used interchangeably. Quality of life is about an individual's personal, subjective experience and perception of his or her attitude to practical, daily life, other people, society at large and nature around us.

The Norwegian researcher Siri Næss uses the term "quality of life" as a psychological welfare indicator and raises the question of the relationship between a society's conditions and the quality of life of the individuals who live in that society. As a result, research into the quality of life focuses on the question of how society is to be formed and what conditions we should place emphasis on, in order for the citizens of a society to have as good lives as possible.

EXTERNAL LIFE	INTERPERSONAL RELATIONSHIPS	INNER PSYCHOLOGICAL CONDITIONS
residence economic	close relationship friendship like to be with	activity ability to make decisions safety happiness

(Kajandi, Madis, 1981-89)

Some aspects of the term "Quality of life":
We know that deafblindness leads to particularly great problems in:

- communicating
- acquiring information and finding out what is happening where and when
- orientation and mobility
- carrying our practical tasks

These are preconditions for maintenance of social interaction and independent life. The quality of life will depend on the arrangements society makes, including compensatory measures and various forms of help and support schemes.
However, we must assume that there are great individual variations, depending, among other things, on how the person lived as a seeing and hearing individual, his or her interests and the expectations the person has had as to his or her old age. Quality of life is not a static condition – needs and desires change depending on the phase of life one is in, and they are experienced subjectively.
In general, we know that people normally have to slow down a little as they get older – they have less endurance, a lower ability to concentrate and are physical weaker, etc. The oldest of the elderly run an ever increasing risk of illness.
The elderly are more at risk than the rest of us of experiencing losses and break-ups, with the shock and mourning reactions that these entail. Many others experience a change of lifestyle, such as moving to a nursing home. Deafblindness in old age will generally reinforce these tendencies and, owing to their visual and auditory problems, elderly deafblind people have special functional difficulties in mastering the activities and tasks they used to do and in which they were interested. Their levels of activity will normally decline and they will discontinue activities.

However, it seems that the person's experiences of whether their visual and auditory impairments negatively affect their activities are dependent on whether or nor they have other disabilities and their general state of health.

One person answered as follows: "I think the fact that I have lost my leg is much worse than my loss and vision and hearing."

I will use the framework (enclosed) to describe some of the needs that were discovered and must be met to promote independence. To meet needs on different levels and in various areas we must have a multidisciplinary approach in our work, otherwise we will not be able to look at the deafblind person's needs as a whole. Marja Lena has been focusing on psychological and social needs, I want first of all to focus on medical needs for consulting specialists (vision and hearing) to diagnose and make examinations/assessments. We know that getting the correct aids depends on a diagnosis as early as possible.

50% had an eye examination during the last 2 years. Very few knew the diagnosis, but many had been told that "Nothing can be done". That was such a depressing experience for the persons that it was hard to motivate for a new ophthalmological examination as a basic for improving aids.

People with developing disabilities (like macula degeneration, cataract, and glaucoma) had not visited an eye specialist for years. They missed information about their visual function and possibilities for compensation.

" No one has told me before", they said.

Very few had visited an ear-nose-throat specialist during the last 2 years. None knew their hearing diagnosis and the elderly people had no information about their functional hearing. All of the persons we visited had hearing aids, so therefore they must have been to an auditory examination but they did not get information on the results. Even the staff in institutions did not know.

At staff level there is a need for knowledge and awareness about this lack of diagnosis and information. It is needed to establish routines for visual and auditory tests, which should be part of the admission procedure at institutions for the elderly. If not, the visual and auditory problems are not paid attention to in rehabilitation.

Getting adequate help and services depends on a diagnosis as early as possible. Often the severe visual and hearing impairment consequences appear after the age of 80; many of the elderly are not diagnosed before these severe functional problems are obvious. The local authority health service could provide visual and hearing screening at retirement age i.e. the elderly should be diagnosed earlier.

Since there are no traditions in the Norwegian health services to treat visual and auditory impairments as one impairment, better routines are necessary to ensure co-operation between the specialist for sight and hearing. There also are needs for "following-up" routines concerned with different kinds of progressive disabilities.

Communication:
70% of the persons had serious problems in one-to-one conversations and the whole group stated that they had severe problems in groups like family gatherings. It was difficult for them to use aids in such situations, and they felt embarrassed at not recognise persons they met or when meeting unknown people.
The majority therefore, had stopped attending social gatherings.

Mobility and orientation
All those asked said they had great problems going out alone and were dependent on a companion or transport to get out. 80% also stated they found it very difficult to get their bearings and move around indoors if they were not familiar with a place. The reasons for this reduced mobility lay in both their visual and auditory problems, but were also due to a reduction in the use of their limbs that led to problems in walking. A high percentage were therefore dependent on aids to help them move, such as walking frames/Zimmers and wheelchairs, and could not move outdoors without a companion or car transport.
One of the challenges we were given by them was: how can a deafblind person with a walking frame let people know that he or she is deafblind?
When a person's mobility and physical and social activities are strongly reduced, it is important to carry on with individual, seated indoor activities, such as reading, listening to the radio/TV or cassettes, sewing or knitting, etc.
60 of 80 persons could not read normal newspaper writing, but twice as many could read large writing by using aids. CCTV (Close circuit TV) was the only solution for many who could no longer use a magnifying glass. It was important to improve lighting and seating.
Many people could use what was left of their hearing to listen to the radio/cassettes by using the correct aids. Those who were dependent on a loud volume from the radio or tape recorder and who lived with others did not want to disturb their co-residents and were very pleased to get aids such as a loop system and other amplification aids.

Environment design
The elderly living in institutions had almost no social interaction with other elderly persons. They stayed in their rooms most of the time, and did not participate in social activities any more.
An old lady said: "When I went to the 'day room', a woman used to say: There she comes 'the noisy woman'". That was because she had a hearing aid which was not adjusted and therefore was always making a "peep".
2 of 10 institutions had a loop system installed. So there really are challenges in this field of "Environment design". Much can be done through minor measures.
Video examples.
The interview with the elderly persons showed that compensatory measures such as technical aids are very important for reducing the disabling effect of deafblindness and

raising their quality of life. One of the measures on the staff level is to provide some basic information for the staff in local services. In Norway we intend to send an information video "When vision and hearing fail" to the Social and Health services in the municipalities. Some examples from the video were shown.

It is important for the consultant and the deafblind person to know each other well and have a good personal relationship, and the consultant must have plenty of time.

Motivation is an important element. Quote: "I'm too old to learn now".

In practice, it appears that if deafblind people are allowed to try out the aid at home, in activities in which they are interested, motivation comes naturally because they can see the benefit of using the aid. For example, CCTV can be used to read letters from the family of the deafblind person.

This workshop placed great emphasis on compensatory measures, such as aids. Psychosocial help and support are more important to many people than all the aids in the world, but there is often a need for all of these because technical aids mean that people can continue with activities and they help the person to master things and live an independent, "normalised" life. But the technical aids must not be a compensation for social interaction and help from human beings.

The elderly were offered interpreter/companion services and contact-person services, but most of them were sceptical about these because they involved meeting unknown people. Many people also wanted to manage themselves. This is an important consideration with regard to today's elderly and measures to help them: many of them are unassuming and do not want to be any trouble. Perhaps this attitude to receiving help and demanding one's rights will change once today's younger generation grows old?

A PROGRAMME IN NORTHERN IRELAND

Richard Devlin (Northern Ireland)

The workshop was presented by Richard Devlin, Community Services Manager for Sense in Northern Ireland. Part of his role is to take a lead in developing service programmes within community sector services in the Province.

The programme of the workshop title is essentially an initiative under discussion. The project concept is to establish Guide Communicator services using trained and supported older, currently unemployed, people. The area to be targeted would be North and West Belfast and potential clients would be identified by local Health and Social Services trusts. This would take advantage of an already established sense of community and areas with high levels of older unemployment, which have also been identified as having a higher incidence of disability. Exploratory discussions have already taken place between Sense and the Training and Employment Agency, Springvale Training Organisation and the North and West Belfast Health and Social Services Trusts.

PARTICIPANTS SHARED THEIR VIEWS ON THIS PROJECT AND DISCUSSED MERITS AND DRAWBACKS

A brief resume of the points raised:

- Does the mere fact of being older oneself mean one can altogether identify with the needs of one's peers? How well do the attitudes and thinking of a 50 year old accord with a 70+ year old?
- This appears to be a new concept. Other projects with elderly people are known, for instance in The Netherlands, but are generally run more informally with volunteers.
- How would funding be decided and guaranteed for this work?
- The selection process would need to be very carefully executed - i.e. one needed to be aware of attracting "care takers" who are themselves people who need to be needed and are needy personalities.
- It would be vital to develop a philosophy for the project which would in turn produce a working Mission statement and drive training forward. This would also encourage trainees to "buy into" the project and gain a sense of personal ownership.
- Where might be the best place to look for potential trainees? It was agreed that it

might be difficult to look in the social network of the client, at friends or neighbours, as this would radically change the nature of the relationship. It was felt that there was a need for some "distance" between the client and his/her Guide Communicator.

- It was also necessary to take into consideration that religious questions are highly relevant to Northern Irish society and to anticipate some allied difficulties in setting up these schemes.
- On the question of skills, it was suggested that anyone "too" experienced or skilled may be too expensive for this project. Unemployed benefits levels would also need to be addressed for the unemployed person to take on paid work as Guide Communicators.
- On the question of funding, ultimately Social Services Trusts would be responsible but there could be several possibilities of joint client / SSD funding through Independent Living Fund payments or with the newly introduced client Direct Payments for services system.
- Do communities with the positive characteristics found in Northern Ireland still exist elsewhere in Europe, and therefore could this kind of project translate to other countries? Other examples of similar services were discussed, with a clear outline given about the following schemes:
  a) The Confident Living Programme from the USA; this based on a service offered in Australia, where the "Buddy" system has developed and Guides are closely monitored and supported by skilled and experienced staff.
  b) The contact person scheme in Denmark
  c) The home instructors scheme in Sweden
  d) The Guide Communicator schemes in Bradford (UK) where some Guides are older.
- Some doubts were expressed regarding the use of unemployed people but no doubts at all that all services needed to be encouraged and nurtured wherever possible. Neither did the group altogether subscribe to Leonard Cohen's wry look at growing older: "Well, my hearing's gone and my hair is grey, and I ache in the places where I used to play". The mood was more upbeat about age, with a qualified thumbs up to the Older Peoples Training Initiative. Unfortunately, none of us could come up with a snappy title based on the first four letters OPTI.

All thoughts welcome!

ELDERLY DEAFBLINDNESS CLOSING SESSION

Marjanna Suosalmi (Finland)
Malcolm Matthews (United Kingdom)

Malcolm Matthews drew out some of the themes and conclusions from the conference:

Themes and issues

All of us will have had different experiences during this conference and how we interpret those experiences depends on the context, what we have experienced before, our previous experience and knowledge. My experience is not necessarily the same of yours and – of course – my account of the themes can only be partial as I did not go to all the workshops!

Starting point

Kirsten told us how recently work with older people with both a vision and hearing loss developed. This is the first conference focusing on this specific group – although there was a meeting in Copenhagen a few months ago on older deafblind people which brought together professionals from various countries. For the first time, they were able to share their expertise with others with similar experiences. There they were not in the role of being an expert with other people coming to them for information and knowledge; they were colleagues sharing and communicating with each other and developing their expertise. This conference has carried that process further, including new people and widening the debate. Earlier Marjanna asked whether the right people are attending this conference? Should we have had more people from the elderly field, people with medical expertise, or policy makers? These questions must be addressed; but perhaps the people who are here today are the right people to begin the development of work for older people with dual sensory loss – the right people for this stage of development of the field. We are at the beginning and have to sort out a lot of issues. For example, how many older deafblind people are there? I suggested 150 deafblind people per 100,000 elderly people in the population in my presentation. Later we heard that in Norway the figure may be as high as 188 per 100,000. In Finland 700 per 100,0000 have been found. We need to look at this significant difference. If the results from Finland are true for other parts of Europe, then we need to reconsider what messages we have to disseminate.

Awareness raising

Kirsten talked about the first rule in the United Nations document. This concerns awareness raising.

I am surprised that there appears to be so little awareness of the problem concerning older people with dual sensory impairment.
The question I raised in my presentation was: do we want to do anything about the attitudes within society, culture and ageism? I believe we need to operate on two levels :

- raising awareness on dual sensory loss
- changing the way our society looks at older people

I do not think we will be successful in one if we do not work at the other too.
In the workshop on campaigning we had the dilemma about the use of the term "deafblind" with people who develop both a sight and hearing loss in old age. "Deafblind" is fine when we are working as professionals and are considering what we can do; but it is problematic for people with dual sensory impairment, policy makers and professionals out of the field. Kirsten said: we can't be successful by ourselves, we need more actors. If we want more actors we need to agree a common language.

Expertise
We are going to see the TV interview later at which I was asked the question: what can you do about deafblind older people? I said that a lot can be done; I probably should have said that we have to develop our expertise further. We need to evaluate, compare and learn; both within and between our different countries. We also need to make use of the expertise of those who are specialist in the elderly field.
There is now some good practice in different parts of Europe.
Communication was one of the main topics of this seminar. The guidelines were disseminated as the key to meeting peoples' needs. They also focus on staff and families. This came up too in other presentations, in particular in sessions on staff training.
We also have some conflicting ideas (unless my understanding is wrong). I think of the work of Jan in Kalorama where he focused on rehabilitation in two different ways. He suggested rehabilitation oriented on functioning is more important than rehabilitation oriented on development and training. For some people, quality of life could be achieved even though communication is not achieved. I don't think this would be accepted by everybody. However, the important thing is that we start to debate and develop critical ideas about our practice. It shows that even such a new field is beginning to mature.

Policy and strategy
It was intended that policy and strategy would be one of the themes of the seminar. We need to operate at the level of each state. Jeff talked about a national initiative called "Think Dual Sensory" which has had a very real effect on the level of services in U.K. However, it is not just at the level of the state that policy is important. We heard about Bradford where a policy statement there has led to new services.

The structures that we have are particularly problematic for this group; services for blind people, deaf people and older people are structured separately.
We have not talked about resources which is the key to services; for decisions to be made, we have to deal with awareness and prove that the services can be delivered.
We need to work on prevention – to encourage intervention and provision of support and aids and equipment when sensory loss develops - before we reach the crisis point for an individual of communication becoming virtually impossible and learning becoming extremely difficult.

Quality of life
Ann Svenson reported about the expressed needs of older people. Older people want to be useful. They want to talk about their experiences and help others. In the video Hazel's greatest regret was to have lost the friend that she cared for and so to no longer be useful to and caring for another person. Nancy on the video had a role in looking after a tortoise, preparing meals and caring for it. We need to do more to encourage the participation and involvement of older people. We also heard about older people learning together and of the importance of peer support. In Richard's works, he mentioned the possibility of older people as volunteers.

Emotional issues
A number of the presentation have had a distressing element. Liz talked about Elkie dying; Hazel talking of life not being bad, but being emotionally upset as she said this. Ann Svensson did not paint a happy picture of the emotional life of older people, and the same could be said about Jeff Bashton's quotes. However, two thing balanced against that distress: the passion which has been present in this seminar, the desire to bring about change and work together at the level of policy and practice development and to try to change attitudes.
The final emotion which has been a part of this experience could be described as the happiness or the elation which comes from finding colleagues to work with and who understand what you are trying to do, who face the same problems, people who can help us and who we can help.

Towards the end of the conference a survey had been undertaken of participant's ideas and plans for the future. Marjanna reported on the outcomes:

Main activities in the future
Awareness / Advocacy
Many reported that they want to raise awareness in their own organisation. Several mentioned local services: home care, nursing homes, home services, non specialists, eye and ear clinics. Others propose to lobby, promote advocacy of the deafblind, or advocate

for more counsellors, and more and better services
The question of definition was also mentioned : it is easier to advocate when you really know what you are talking about.

Information
22 persons are working on awareness.
16 are working at the level of information. They want to inform colleagues, local authorities, nursing homes, eye clinics on hearing and ear clinics on vision.
Some people wanted to highlight and produce material about good practice.

Staff training
4 persons are concerned with staff development and want to train non specialists, specialists and volunteer organisations. Somebody wanted also to have a state of the art conference to get new knowledge.

Services
13 work for services for elderly deafblind people. Some work with Usher groups, train people on technical aids and mobility etc. Some work with counselling.

Projects
20 persons reported about developmental work.
The first group is those who develop services.
Others work with the system of services in the country
Some work at establishing new nursing homes or new institutions, resources services, translating material etc.
Others work with the population, get information, identify it and assess it.
Other people work at looking for new ways to work, new strategies in organisation.
The internet and multi-linguism were also mentioned.

Co-operation
Some people want to make links with eye or ear professionals.
Some want multidisciplinary work and liaison with colleagues (internally and externally).
Some want to visit other centres, create networks etc.
So a lot is done. How are we going to rationalise this future.

Follow up
Most mention that the follow up is important for learning more, supporting each other etc.
We are rather isolated in our countries.
Very many felt that this conference must be followed up at a national level.
Many suggested trans-national activities on communication for instance. A very concrete

suggestion was a focus day in Lisbon next year[1]. It in not too late to send abstracts.
European expert conferences are also suggested. Many felt that this kind of European could be arranged every other year. Many felt there should be more new information? At this conference we partly repeated things that are already known. We need more interactive conferences, especially on issues that we do not have answers to. The conference could focus on the real nature of deafblindness. Some think that people coming from technical fields could be invited. We would need working groups developing theory and practice on the issues we address.
Other suggested activities: newsletters etc. Those working in Resources services insist on the validity of written information!
Others mentioned that Deafblind persons should be heard in this context.
Discussion
Martha would like to have a world conference on older deafblind people. Some people from Australia would probably be keen to participate.
Malcolm explained that we did talk about having a world-wide campaign – and we recognised the need to work at a world, European and national levels. Perhaps the Acquired Deafblindness Network has a role developing and disseminating material on awareness that could be used at national levels by local and national organisations.
The UN year on elderly people might be an opportunity to spread awareness.

Marajanna summarises:

1- We have to work at a national level with different topics.
2- We have the possibility of raising the problem of this group in Lisbon.
3- In two years time, we could organise a conference to report on the national work.
4- We cannot decide if we need a network targeted on older deafblind people. But this group, among the acquired deafblind people should be addressed specifically.
5- We need information from other countries, and in written form. It is important that when you make a project report in your own language, that you also prepare an English summary, so that other people can share the results or give the report to the Network.
6- Deafblindness is so difficult to understand, that you need a lot of knowledge. Therefore, co-operation is needed for this group. I hope the focus on the elderly next UN year will have a positive effect for the elderly with dual sensory impairments.

1 The Acquired Deafblindness Network will host a half day option at the 12th DbI World Conference in Lisbon in July 1999.

ACQUIRED DEAFBLINDNESS NETWORK

Malcolm Matthews (UK)

Following on from the main Conference an open meeting was held to discuss the future work of the Acquired Deafblind Network and to enable conference participants to contribute and influence the development of activities. Anneke Balder chaired the session and Malcolm Matthews outlined the role and work to date of the Network and drew conclusions from the debate. The following notes were prepared as a result of the discussion.

Notes from an open meeting

The Acquired Deafblindness Network is a network of professionals who are involved in working with people with acquired deafblindness, and facilitates exchange of ideas and experience, and development of new knowledge through international co-operation.

The Network is part of Deafblind International (DbI), the world organisation for professionals in the field of deafblindness.

In the field of acquired deafblindness there are relatively few professionals. They work alone, most often with no local network of colleagues, and there is a great need for forums for professional discussions and support. The Network provides such a forum at a European level.

The following functions and activities were agreed as the priorities for the Acquired Deafblindness Network of Deafblind International. The activities were considered as applying to Europe but consideration should be given to inclusion of people from elsewhere and to activity at a world level.

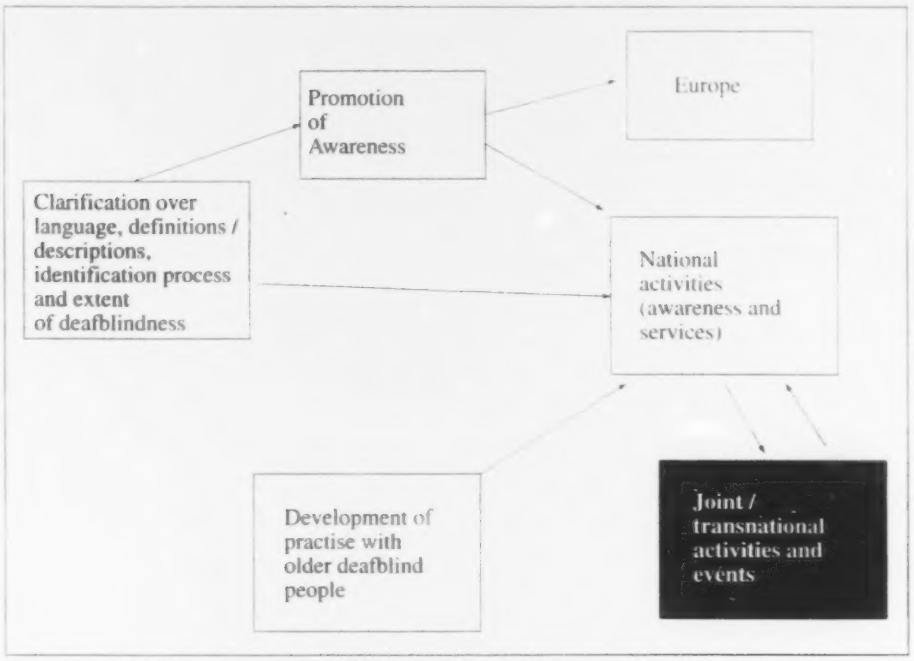
Function 1

To raise awareness of acquired deafblindness at a Europeaa level, and to help enable awareness raising at a national level.

Function 2

To facilitate the development of the acquired deafblindness field, especially through collaboration and joint actions between countries.

Various activities were agreed as being required in order to undertake these functions.


Promotion of Awareness
Europe
Clarification over language, definitions / descriptions, identification process and extent of deafblindness
National activities (awareness and services)
Development of practise with older deafblind people
Joint / transnational activities and events

Promotion of awareness is an activity targeted at bringing about change at a European level. The aim is also to assist national awareness activity through provision of information and materials.

Clarification over language, definitions / descriptions, the identification process and the extent of deafblindness is needed in order to be able to undertake promotion and campaigning at a European level. It is recognised that different definitions may be employed in practise in different countries because of the different cultural contexts but some agreement and clarity is necessary at a European level if we are to influence others e.g. we must have a consistent vocabulary (for example, agree to use of the expression "people with both a vision and hearing loss in old age", agree what this means and agree the number of such persons). Such decisions would then be useful at a national level over awareness raising.

Development of practise with older deafblind people is a specific objective that practitioners will wish to work on. Activities will include production of materials (such as the already prepared Guidelines on Communication).

Joint / transnational activities and events might be to further the aims associated with other activities e.g. development of practise.

Events such as seminars may be organised and a conference is proposed at a European or world level, to be held when the other activities have led to the generation of content for dissemination.
A main activity within all Acquired Deafblindness Network activities is writing up, producing information and dissemination.
There is also a co-ordination role which is the responsibility of the Development Group. A suggestion is that the Group may involve one or more people involved in each activity. Another suggestion is that we might have one person with the responsibility of being the link person for each country.
People are needed to undertake the work associated with these activities including involvement in the Development Group. Groups wishing to work on particular activities may do this through written (fax and email) and telephone communication, or if the participants have the necessary resources, then meetings may be undertaken.
Membership of the Network involves at a minimum providing information for the Contact List. This will be updated and circulated on a regular basis.
Information on the Network will be available in DbI Review and on the DbI web page.

For more information on the Acquired Deafblind Network contact
Anneke Balder
Stichting Doof-Blinden
P.O. Box 222
3500 AE UTRECHT
The Netherlands
Telephone: +31 30 276 99 70
Fax: +31 30 271 28 92
E-mail: sdg@wxs.nl

For more information on Deafblind International contact
Tamar Underhill
Assistant Secretary
DbI Secretariat
11-13 Clifton Terrace
London N4 3SR
Telephone +44 171 272 7774
Fax +44 171 272 6012
E-mail tunerhill@sense.org.uk

The DbI web page is at http://www.sense.org.uk/sense/html/dbi.htm

And finally ...

The working languages of the conference were English and Italian.

The conference was organised under the auspices of the Acquired Deafblind Network of Deafblind International.

The Programme Planning Committee was:
Anneke Balder, The Netherlands
Jean François Guérineau, France
Malcolm Matthews, UK
Ole E Mortensen, Denmark
Ann Svensson, Sweden.

Local organisation was undertaken by:
William Green with administrative and practical support from:
Rossano Bartoli, Alessandra Broccolo, Sandro Coltrinari, Carmelo Totaro

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Editing: Malcolm Mathews and William Green.
Some changes were made to texts submitted for these proceedings where translation was unclear. There has also been some minor editing. Apologies to authors if their intended meaning has inadvertently been corrupted.

The proceedings are also available on disk.

To join the Acquired Deafblind Network Contact List please write to:
Anneke Balder
Stichting Doof-Blinden
P.O. Box 222
Q 3500 AE UTRECHT
The Netherlands

Participants

Marianne Dwarshuis
Eurolink Age
Place du Luxembourg 1
1050 Brussels
Belgium

Cosimo Lupo
UCBA
Schutzengasse 4
9001 St. Gallen
Switzerland

Marija Barsic
UCBA
Schutzengasse 4
9001 St. Gallen
Switzerland

Hilde Verhees
UCBA
Schutzengasse 4
9001 St. Gallen
Switzerland

Anny Koppen
Nordic Staff Training Center for
Deafblind Services
Slotsgade 8
Dronninglund DK 9330
Denmark

Ole Mortensen
Acquired Deafblindness
Generatorvej 2A
DK-2730 Herlew
Denmark

Kirsten Jansbol
Acquired Deafblindness
Generatorvej 2A
DK-2730 Herlew
Denmark

Elsa M. Jensen
Institutionen dor dove
Generatorvej 2A
DK-2730 Herlew
Denmark

Jacques Souriau
Centre de Ressorces
Cessa Larnay
86500 Biard
France

J.F. Guerineau
CAT
131 Ave De la Haute Chaume
82280 Saint Benoit
France

Marja Leena Saarinen
The Service Foundation for the deaf
Tapion Katu 4A
40100 Jyvaskyna
Finland

Kirsti Tamminen
Finnish Deafblind Association
The Residential Activity Center
for the Deafblind
Virtaindolku 2
33720 Tampere
Finland

Karl Heinz Jacobs
Taublindwerk
Albert Shweitzer Hoff 27
30559 Hannover
Germany

William Green
Lega del Filo d'Oro
Via Montecerno 1
60027 Osimo
Italy

D. Acerbi
Comunità Alloggio
Lega del Filo d'Oro MI
Via Carlo Poma 48
20129 Milano
Italy

S. Passeri
Comunità Alloggio
Lega del Filo d'Oro MI
Via Carlo Poma 48
20129 Milano
Italy

V. Casale
Comunità Alloggio
Lega del Filo d'Oro MI
Via Carlo Poma 48
20129 Milano
Italy

S. Corridori
Comunità Alloggio
Lega del Filo d'Oro MI
Via Carlo Poma 48
20129 Milano
Italy

Richard Devlin
Resource Centre
Road Mallusle
Belfast BT 36 6 RU
Northern Ireland

Elisabeth Olafson
Norvegian Central Team for the
Deafblind
PO box 8042 - Dep N-0031
Oslo
Norway

Else Marie Svingen
Norvegian Central Team for the
Deafblind
PO box 8042 - Dep N-0031
Oslo
Norway

Birgit Friele
The Norvegian Ministry of Health
and Social Affairs
PO box 8011 - Dep N-0030
Oslo
Norway

Frank Jorritsma
Bartimeus
3513 EP Utrecht
The Netherlands

Anneke Balder
Stichting Doof-Blinden
P.O. Box 222
3500 AE Utrecht
The Netherlands

Lucette Teurlings
Sonneheerdt
P.O. box 600
3850 AP Ermelo
The Netherlands

Saskia Biesterbos
VISIO
Paasheuvelweg 17
Amsterdam 1105 BE
The Netherlands

Monique Mul
VISIO
Gildestraat 3
1704 AG Heerhugowaard
The Netherlands

Yvonne Jansen
Reg Centre Theofaan
Leuvenaorstraatr 93
4811 V J Breda
The Netherlands

A Schaeffer
Reg Centre Theofaan
Leuvenaorstraatr 93
4811 V J Breda
The Netherlands

J.M. Dorjee-Albersen
St. Audiologisen Centrum Eindhoven
Castillielaan 8
Eindhoven 5629 CH
The Netherlands

Jan Prickarts
Kalorama
Nieuwe Holleweg 12
6573 DX Bek Ubbergen
The Netherlands

Ann Svensson
S.H.I. Statens Institute for Handicap
Erik Dahlbergsgat an 11B
41126 Goteborg
Sweden

Anita Bengtsson
Box 230
S-301 06 halmstad
Sweden

Margaretha Lagerdahl
PI 1701
S-311 96 Heberg
Sweden

Marjaana Suosalmi
Kuurojen Palvelusaatio
Ilkantie 4
00100 Helsinki
Finland

Philippa May
Sense South West
Beauworth Moreton Hampstead
Devon TQ 13 8LS
United Kingdom

Marylin Kilsby
SENSE - USHER SERVICES
11-13 Clifton Terrace
London N4 3SR
United Kingdom

Malcom Mathews
SENSE - The national Deafblind
& Rubella Association
11-13 Clifton Terrace
United Kingdom

Steve Alexander
SENSE - The national Deafblind
& Rubella Association
4 Church Road Edgbaston
Birmingham B15 3TD
United Kingdom

Tony Kirk
SENSE - The national Deafblind
& Rubella Association
4 Church Road Edgbaston
Birmingham B15 3TD
United Kingdom

Sarah Goodwin
SENSE - The national Deafblind
& Rubella Association
4 Church Road Edgbaston
Birmingham B15 3TD
United Kingdom

Jeff Bashton
Department of Wealth
Wellington house room 225
133-155 Waterloo Road
London SEI 84G
United Kingdom

Graham Willetts
Royal National Institute for the Blind
RNIB
23 Olivers Way Winborne
Dorset BH21 2LQ
United Kingdom

Brian Peaker
RNIB
28 Ridgeway Tranmere Parte
Guisely L5 20 CJA
United Kingdom

Karen Sandall (int)
SENSE
63 Poole Street
NorthamtonNN 3EX
United Kingdom

Sharon Cox (int)
SENSE
11-13 Clifton Terrance
London N4 3SR
United Kingdom

Rachel Jefferson
SENSE NORTH
122 Westgate
Wf2 8AU Wakefield
United Kingdom

Liz Duncan
SENSE
11-13 Clifton Terrance
London N4 35R
United Kingdom

Martha Bagley
American Printing House for the blind inc
1839 Frankfort Avenue
Lousville Ky 40206-0085
USA

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